My Views Matter

Residential and in-patient care for people with learning disabilities and autism in Norfolk

healthwatch Norfolk

Contents

Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to the people of Norfolk, through us. So, whether people share a good or bad experience with us, their views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather people's views and experiences (good and bad).
2. Pay particular attention to underrepresented groups.
3. Show how we contribute to making services better.
4. Contribute to better signposting of services.
5. Work with national organisations to help create better services.

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Acknowledgements

Healthwatch Norfolk would like to thank Tony Edwards and Lauren Chapman for their assistance as co-researchers on the Enter and View visits. We would also like to thank About with Friends and Nansa for supporting them, and the members of Opening Doors for organising and participating in the focus groups.

Summary

Between April 2018 and July 2020, three patients, Joanna, “Jon” and Ben, died at Cawston Park Hospital in North Norfolk, having suffered neglect and abuse. They were all in their 30s, and they all had learning disabilities. An important finding of reports into the tragedy was that the views of patients and their families were systematically ignored by the hospital. As part of the system response to these events, the Healthwatch Norfolk board agreed to undertake a review of the residential and in-patient sector caring for people with learning disabilities and autistic people.

In line with Healthwatch's mandate this review has looked at three main questions:

1. How have the residential care and secure-inpatient sectors caring for people with learning disabilities and autistic people in Norfolk changed in recent years, and what plans are in place for the future?
2. What mechanisms are in place in the sector to make sure people’s voices are heard and acted upon?
3. What do people using these residential and in-patient services, and their families, think about the care they receive?

To answer the first question, we interviewed 25 professionals working in the sector, and reviewed literature on recent developments in the sector in Norfolk. To answer the second and third questions, we carried out Enter and View visits to 21 residential homes and 4 secure in-patient units, talking to 94 service users. We also interviewed 58 family members, and commissioned a user-led advocacy organisation for people with learning disabilities and autism, Opening Doors, to run focus groups with their members about their experiences of residential care. These were attended by 42 people.

Views from professionals

Most professionals we spoke to expressed concern about the overall state of the residential care sector in Norfolk. People we spoke to at Norfolk County Council (NCC) identified a number of key difficulties. The quality of Norfolk's social care services is rated by the CQC as being lower than in most parts of England, and includes services that are not compliant with current standards, and which would not be commissioned under current frameworks.

The sector in Norfolk was said to face several geographical and historical issues that affect its residential care, some of which make it difficult to recruit care staff. These include having a long coastline, and so fewer neighbouring areas to recruit from, and homes based in rural areas which are less attractive for people to live in and can be expensive to travel to. Norfolk also has a relatively elderly population, with a low proportion of working-age adults, compared to other areas.

In addition, over time, Norfolk has developed a higher proportion of residential care compared to other areas, with a lower proportion of supported living, which, we were told, results in some people becoming de-skilled.

NCC's Integrated Quality Service is giving support to providers to improve the quality of their services, whilst also taking enforcement action against providers who persistently breach their contracts, including closing some services down. They envisage closures of a significant proportion of homes in Norfolk. NCC’s learning disabilities commissioners undertook a consultation exercise in 2020 and 2021 to try to understand what people's families want from the housing for their relatives in care. In response to this consultation and shortfalls that NCC have identified in the sector, NCC has developed a strategy to increase provision of supported living settings, including increased places for people with complex needs. £18 million has been made available to meet the capital costs to start to meet the projected demand.

The council is also seeking to improve the skills base in residential homes by providing Positive Behaviour Support (PBS) training to all providers free of charge.

We spoke to a senior nurse for learning disability quality at Norfolk and Waveney ICS about the physical health of care home residents. She told us that, while there is more oversight of residents' health than there used to be, several problems remain. One is that care staff do not always explain to people the consequences of unhealthy choices, but accept a refusal to eat well and look after their health properly at face value. After a dip during the pandemic, the numbers of people participating in Annual Health Checks has increased to attain the national target. Work is underway to improve the quality of health checks through a network of LD champions in GP surgeries.

We also sought the views of clinicians from the Hertfordshire Partnership NHS Trust Learning Disability and Forensic Services Team about work to prevent admission of people to secure units. They told us that there had been progress in this regard in the past ten years, but that people can still be discharged into settings where staff do not have the expertise to cope with their behaviour. This team includes services to provide a bridge between in-patient units and the community, providing support for people and their community placement staff, before and after they are discharged from secure services, to reduce the risk of (re-)admission.

We also spoke to the Norfolk Care Association, a membership body representing provider organisations in social care, to try to understand the perspective of care home providers. We were told that providers were keen to see the cost implications of NCC's new proposals for residential care, with some being sceptical that funding would be provided to match the increased demands of the new model. Providers were also said to be worried about the difficulty of recruiting care staff, which they consider to be more difficult now than at any other time anyone can remember. This is partly about pay levels that compare poorly to other, less demanding jobs, and is also related to the superior respect, terms and conditions, career progression and salary that workers in the health sector enjoy.

Finally, we spoke to three third-sector organisations who work with people with learning disabilities and advocate with and for them. They had a critical view of the sector, and spoke of people who used their services who had been given inappropriate placements, and who found it very difficult to move to a placement that was appropriate for their level of need, for their preferences and that was close to their friends and family. Problems with the annual review process were also raised, with annual reviews said to be delayed in some cases, being carried out by less-experienced assistant practitioners, rather than social workers, and being carried out by a different person at each review.

Feedback about residential homes

We received most feedback on the following topics, with the following findings:

Shortages of suitable placements

Some relatives reported having been unable to find care placements, particularly for young people transitioning from children's services to adult services.

- Despite the improved support of NCC's preparing for adult life team, many families have been waiting for years for a suitable placement for their young person.
- This is putting considerable strain on the mental health of family carers, and preventing young people from living where they want to.
- Some parents had made the difficult decision to send their young people out of county, or people had spent years in an unsuitable placement before a more suitable one became available.

Norfolk urgently needs to develop more specialist residential and supported living placements, and there needs to be better resourcing to provide places for young people when they become adults.

Listening practices

Homes used a variety of methods to listen to people. These would often include monthly or weekly residents' meetings, and/or more personalised ways of consulting them. Most people we spoke to were happy that they were listened to by staff in the homes, and gave us examples of when this had happened. When people in homes complained that they were not being listened to, it was often because of a negotiation around a person's preferences and their best interests. A minority of residents identified some other problems. Three relatives of people in the homes and five people in the focus groups identified communication and listening problems. Five relatives reported problems with listening and responsiveness in the homes due to staff shortages.

People's relations with care staff

People living in homes were generally very positive about their relations with staff, and did not want to change anything about their staff support. This positive picture was supported by our observations in the homes. Feedback from relatives was also mostly positive, as was feedback from the focus groups.

What mattered most to people about their staff was:

- Reciprocal and non-hierarchical relationships.
- Long-term relationships, particularly for people with communication difficulties or complex needs.
- Family-like, affectionate relationships with staff.
- Staff who know residents well, and know what makes them tick.

People's main concern in this area was high levels of turnover of care staff, since many people find it difficult to adjust emotionally and mentally to the loss of a significant person in their life, and people with communication difficulties often struggle to communicate with new staff.

Managers

Again, most feedback about managers was positive. What mattered most to service users' families in their interactions with managers was:

- Managers who were engaged in the everyday life of the home.
- Managers who knew and understood residents well.
- An approach to disagreements based on open communication, being receptive to suggestions, and clearly prioritising the best interests of the resident over other considerations.

Some relatives and staff spoke to us of the disruption that could ensue when there was a high turnover of managers and were very keen to avoid this.

Premises

The physical aspect of homes could both reflect and facilitate people's control over their homes and their everyday lives within them. We saw a range of different levels of personalisation in homes:

- Most people's bedrooms were well-personalised, but only in a minority of homes were people able to choose how they were decorated.
- Even fewer homes allowed people to have extensive control over the decoration of communal spaces. We also found that more homes could make use of accessible and well-organised information displays, to help people navigate their homes and gain new skills.
- It was comparatively rare to find a culture of ownership and participation where people moved around their home freely and participated in its upkeep on a regular basis.

Activities

What mattered most to people about their activities:

- People with high support needs valued attentive activities support, which combined day-to-day individualised responsiveness and the chance to develop their interests.
- Some people needed encouragement to try new things, and were grateful for this despite their initial reluctance.
- People with lower support needs appreciated support with developing the independence and confidence to be able to go out and participate in activities by themselves.
- Most people were happy with their day services, and many particularly liked the work or work-like activities that they undertook there.

Friendships and relationships

Most people were happy with the support staff provided for maintaining relationships. However:

- Few people managed to maintain friendships established before they moved into their home.
- People's social networks were mostly limited to other disabled people, staff and their families, perhaps suggesting shallow community integration.
- Only one person was engaged in a romantic relationship, suggesting a lack of support in this area.

Homes' interactions with families

Most people were happy with homes’ communications with them, and how they supported relatives to visit homes. However:

- More support could be given to help people visit their elderly parents at home, as they become less able to travel.
- A significant minority of relatives reported being under considerable strain, because they kept having to check that homes were maintaining appropriate levels of care for their family member.
- Some of these relatives were worried about the adverse consequences for their family member, and for their continued access to their family member, if they kept complaining. More reassurance and safeguards may be needed to ensure that relatives can express themselves freely without negative consequences.

Feedback about secure units

- Patient satisfaction: Many patients did not want to be living in secure units, but most felt that staff did a good job, and that they were treated fairly. A relatively small minority of people disagreed.

- All the units seemed to have thorough mechanisms for gathering feedback and allowing patients to participate in the governance of the units. These included regular Care Programme Approach (CPA) review meetings and Care and Treatment Review (CTR) meetings, ward meetings, inclusion on governance committees, individual meetings with staff and well-understood complaints procedures.

- Our observations suggested that the units had cultures which were open to external scrutiny, and they actively elicited negative feedback from patients.

- There are blockages preventing timely discharge, including some legal delays, particularly delays in the processing of Deprivation of Liberty requests by the Court of Protection. The biggest and most difficult problem, however, is the lack of suitable community placements for people to be discharged into.

    - These delays are worrying, and some patients are still facing unacceptably long delays to discharge, particularly from the Assessment and Treatment Unit, with one person having been there for four years.

    - NCC’s new housing programme seems to be helping to clear some of this backlog, but it remains to be seen whether it will be sufficient to cope with all of current or future demand.

Feedback on the broader health and social care system in Norfolk

Some of the feedback that we received was not only about residential and in-patient service providers, but related to how they were supported by the broader health and social care system in Norfolk. Relatives spoke to us most about their family members' experiences with social workers and GPs. Most people we spoke to were happy with their experience of annual reviews with social workers, but five people mentioned that they found relations with social workers more difficult now that they did not have the same social worker for each annual review. This was particularly difficult for some people with learning disabilities, because it could take a long time to understand properly how they like to communicate and what their personality is like. Four people also told us that they found it hard to get a response from social services when they contacted them between reviews.

In all the homes that we visited, all of the residents were up to date with their annual health checks with their GPs, and almost all of the feedback that we received about GP surgeries was positive, with a few isolated exceptions.

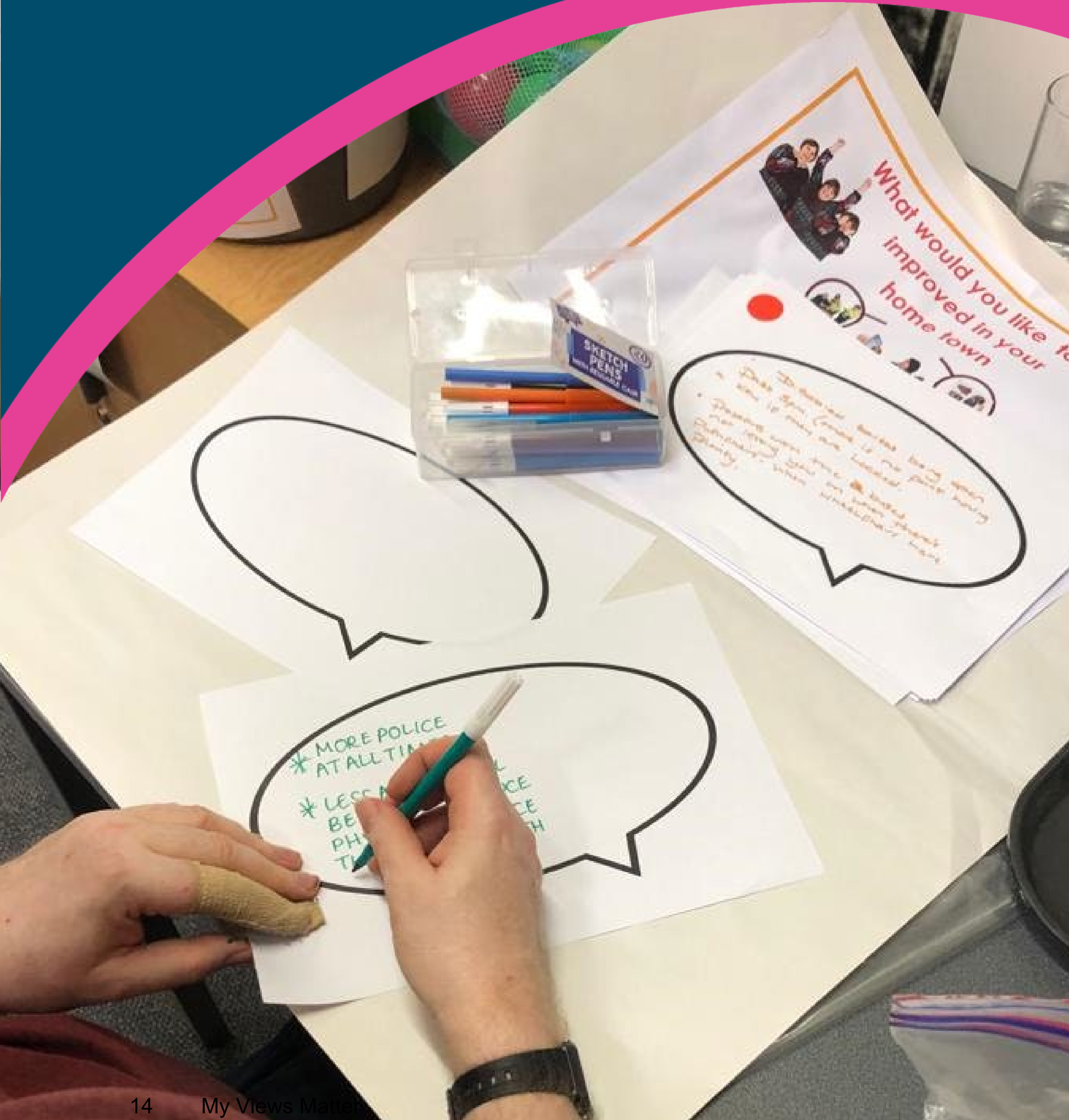
Glossary

Glossary	
Autism	Autism spectrum disorder (ASD). People with ASD think about, experience and interact with the world in a different way to most people. ASD is highly variable, but some features of autism can make it hard for people to express themselves in social situations, and to understand how other people think or feel.
CPA	Care Programme Approach
CQC	Care Quality Commission
CTR	Care and Treatment Review
DOLS	Deprivation of Liberty Safeguard
HWN	Healthwatch Norfolk
IQS	Integrated Quality Service of Norfolk County Council
Learning disability	A condition which means someone may take longer to learn new things throughout their life, and may need support with some aspects of their everyday lives.
NANSA DRAGONS	Norfolk and Norwich SEND Association Disability Real Action Group of Norfolk

SAR	Safeguarding Adults Review
In-patient unit	A hospital unit where people are admitted for treatment, usually either because their behaviour has become too difficult to manage at home, they pose a serious risk to themselves or others, they have a serious mental health problem, or they have committed a criminal act, and their admission has been ordered by a Court.

Introduction

The background to this work and how we gathered feedback



Why we looked at this

Between April 2018 and July 2020, three patients, Joanna, “Jon” and Ben, died at Cawston Park Hospital in North Norfolk, having suffered neglect and abuse. They were all in their 30s, and they all had learning disabilities. The report published by the Care Quality Commission (May 2021) and the Norfolk Safeguarding Adults’ Board (NSAB) Safeguarding Adults Review (SAR) report (September 2021) found major failures of governance, commissioning, and oversight at the hospital. The SAR report and its recommendations can be found at: https://www.norfolksafeguardingadultsboard.info/publications-info-resources/safeguarding-adults-reviews/joanna-jon-and-ben-published-september-2021/.

Another important finding of these reports was that the views of patients and their families were systematically ignored by the hospital. The SAR report pointed out the lack of family-centred approaches, and the failure to engage with the expertise of patients’ relatives. Indeed, the report details that patients’ desire to stay close to their families had been viewed by staff at the hospital as a psychological attachment problem, and by a social worker as a problem of parental over-involvement.

At its meeting in October 2021, the Healthwatch Norfolk Board (HWN) agreed to work with other organisations to jointly respond to the outcomes and explore the actions proposed in the SAR. Given that a failure to listen to patients and their family members was so prominent in this case, it was agreed that HWN’s contribution would be to undertake a review of listening practices across the sector, and gather feedback from service users and their relatives about the care that they receive. As part of this work, HWN agreed to also investigate developments in the sector over recent years to see how it has evolved.

A failure to listen properly to patients and service users with learning disabilities and autistic people is not a new problem, nor one that is limited to Norfolk. After discovery of abuse and failings at Winterbourne View Hospital in 2011 and the launch of the Transforming Care programme in 2013, there was a commitment to “transform services so that people no longer live inappropriately in hospitals but are cared for in line with best practice, based on their individual needs, and that their wishes and those of their families are listened to and are at the heart of planning and delivering their care” (Department of Health, 2012, p. 9). Indeed, Healthwatch Norfolk commissioned a series of Enter and View visits to residential settings for people with learning disabilities and autistic people in 2014 (https://healthwatchnorfolk.co.uk/wp-content/uploads/2023/07/Enter-and-View-residential-settings-for-adults-with-LD-and-autism-March-2014.pdf), partly in response to the events at Winterbourne view. However, more than ten years after Winterbourne View, many still believe that the voices of service users and their families are not being heeded sufficiently (Mencap and the Challenging Behaviour Foundation, 2021; Evans, 2022).

After consulting with the communications group at About with Friends, a learning disabilities charity based in Cromer, it was decided to call the project My Views Matter. The project aimed to answer three main questions:

1. How have the residential care and secure-inpatient sectors caring for people with learning disabilities and autistic people in Norfolk changed in recent years, and what plans are in place for the future?
2. What mechanisms are in place in the sector to make sure people's voices are heard and acted upon?
3. What do people using these residential and in-patient services, and their families, think about the care they receive?

The objective in answering these questions was to ensure the voice of those with learning disabilities/autism and their experiences are heard by those who commission and provide services with particular emphasis on people's qualitative experience. We were also seeking to demonstrate to all involved (commissioners, providers, service users, their families, carers and social workers) examples of best practice. Given that the goal was to gain an overview of the sector as a whole, the methodology was intended to focus on trying to capture a wide range of experiences from across Norfolk, rather than to spend large amounts of time with a smaller group of service users, which would have yielded a more in-depth, but narrower perspective.

How we looked at this

Our research approach

In order to answer our research questions, we needed to find ways to mitigate some of the challenges of doing research in residential homes and inpatient units among people with learning disabilities and autistic people. We identified two main challenges in trying to get reliable data from research in these settings. The first is, that it is very difficult for researchers to know what the everyday life in a residential home is, because they are usually limited to short visits to the home, meaning that they are only able to gain a snapshot of what life in the home is like (see, for example, Dale and Ryan, 2011). This problem has often been noted when abuses have been uncovered in care homes by undercover journalists with recording devices, rather than by professionals on inspection visits.

The second challenge is that it can be difficult for researchers to understand how people in these groups communicate, particularly if they are non-verbal. Learning how to understand how such a person communicates can be time-consuming, and often varies from person to person. This means that during a short visit to a home, it can be difficult to understand what someone thinks about that service. There are also some challenges for researchers trying to successfully interview people with learning disabilities who can express themselves verbally, and adjustments need to be made to interviewing techniques if they are to be effective. In addition, it is possible that residents and in-patients will be less willing to give negative feedback about the place that they live in, when members of staff can overhear their comments.

Our approach to data collection in this project was adapted to try to mitigate these problems, through a triangulated approach. By this, we mean an approach where different sources of information were gathered and compared against one another to check whether they were reliable. The research had three main components.

1. Enter and View visits to residential homes and inpatient units.

Our main research tool was to carry out Enter and View visits to residential homes and secure in-patient units. The purpose of Enter and View visits is to see and hear how people experience care. Social care service providers with publicly-funded service users have a duty to allow representatives of local Healthwatch organisations to enter their premises for this purpose, under the local Government and Public Involvement in Health Act 2007 (as amended by the Health and Social Care act 2012) and National

Health Service Act 2006/Local Government and Public Involvement in Health Act 2007 (as amended by the Local Authorities (Public Health Functions and Entry to Premises by Local Healthwatch Representatives) Regulations 2013). Enter and View visits typically involve a 2-3 hour visit, during which we look around the premises and talk to the people using the service about things that they like about the service and anything that they would like to see changed. We carried out Enter and View visits to 21 residential homes and four secure in-patient units.

We selected residential homes to visit based on criteria that professionals told us were likely to affect the quality of care that people receive. We first reviewed information on all of the homes looking after people with learning disabilities and autistic people, and then selected a sample of 21 homes that reflected our sampling criteria in the same proportions as the full list of homes. The criteria that we used were:

1. Location
    a. North, South, East, West and Central parts of Norfolk.
    b. Urban and rural areas.
    c. Coastal areas.
    d. Areas near the county boundary.
2. Different sizes of home, based on number of residents, from 2 to 36.
3. Different sizes of provider running the home, from independent providers, to one running 136 homes.
4. Different CQC ratings.

Since there are far fewer in-patient units in Norfolk, we selected units to visit based on the different types of unit. We selected one unit each from each of the following categories: medium secure, low secure, rehabilitation, and assessment and treatment.

Observations and conversations

Our visits to homes were announced in advance, to minimise the disruption to people's lives and to give managers the chance to explain to residents in advance that we were coming in, and the purpose of the visit. This would give residents the chance to raise any objections to our visit or to decline to get involved, and to be prepared if they struggled with interruptions to their usual routine. We sent posters to homes in advance of our visits, with photos of the visit team on them, so that people knew who to expect when the visit happened. During the visits, we explained the purpose of our visit to people with the capacity to understand, and asked for their consent to talk to them. If, during a conversation, someone showed signs of becoming upset or anxious, or their body language suggested that they no longer wished to continue, then we stopped the conversation.

An advantage that these visits have over just using interviews is that they allowed us to talk to people about their care in a setting where they could refer to tangible objects and places in their home as they spoke to us. This can make conversations easier for those who find abstract thought difficult. Using observation combined with conversations also allowed us to ask better questions about their experience of services because we had concrete, specific examples about their day-to-day lives to talk to them about. This process also helped us to get an idea of how a person living in a home viewed the premises, as we could, for example, ask a resident to give us a tour of the house, and ask questions about how they viewed different parts of it.

When interviewing people in the homes, we drew on advice in the academic literature on interviewing people with learning disabilities and autistic people, about gaining reliable findings. This involved adopting an approach that can minimise potential errors related to acquiescence (when some people tend to answer yes to all yes/no questions), nay-saying (when some people tend to answer no to all yes/no questions) and recency (when people mostly choose the last item in a list of options). To try to overcome these problems we only considered an answer to a question be reliable, if someone gave us some extra information to back up their spoken response. For example, a 'yes' spoken in a non-committal way would not carry as much weight as a 'yes' accompanied by enthusiastic tone of voice and vigorous nodding of the head. So, such an answer would require follow up questions to try to get some more detail about their response, to make sure that we had understood correctly. Where we could not get this kind of supporting evidence, we would discard the response.

We would also, where possible, speak to keyworkers or other staff members who knew a person well, to double check whether we understood their experience of a service. In cases where we had difficulty communicating with someone, particularly those who were non-verbal, we were more reliant on staff to help us to interpret people's responses.

We asked people a range of questions, starting with the most open questions about their general levels of satisfaction, and anything that they would like to tell us, good and bad, about their home. We would ask follow-up questions about any issues that they raised. Then we would move on to ask questions about staff, relationships, activities, choice and personalisation, aspirations, food and drink, and health.

Make-up of visit teams

We visited services in teams of two or three, depending on the size of the service we were visiting. The visit team would typically comprise the Enter and View co-ordinator (an experienced social researcher), a member of the community engagement team, and a third person, most often an expert by experience.

Our objective was to combine research and engagement expertise, along with lived experience of using services. We worked with one member of About with Friends, a learning disabilities charity promoting the independence of people with learning disabilities, and one member of the NANSA DRAGONS – the Norfolk and Norwich Send Association's Disability Real Action Group of Norfolk. These people were selected because they had experience of both good and bad residential services, and also had some experience either in interviewing, or in carrying out quality checking visits to different services.

These two people were trained in how to undertake an Enter and View visit, how to make observations and how to interview people. They were supported by people from their organisations during this training, and were accompanied by a support person on their first visits. Their role during Enter and View visits was to make observations and to ask any questions that they thought were important, partly based on a list of suggested questions discussed before the visits. After the visit, they were supported to share their observations, and any important points that they thought should be prioritised in the report.

2. In-depth qualitative interviews with relatives of service users

To double check the data that we obtained from the Enter and View visits, we also asked home managers to give us the contacts of residents' relatives who were willing to be interviewed by us. These interviews were mostly carried out by telephone. We asked people a range of questions, again starting with broad questions about their views about the care that their relative was receiving, with follow-up questions on any issues that they raised. We would then ask more specific questions about voice and choice, activities, food, relationships, communication and feedback, health needs, and the process of finding the right home for their relative, and their experience of the annual review process with social services.

We also invited relatives of people in residential care through other channels to get in touch if they wanted to share feedback about their family member's care. We distributed this invitation through our social media accounts and a range of third-sector organisations working in this area.

3. Focus groups run by Opening Doors

To try to provide another perspective on the data that we obtained during visits and relatives' interviews, we also commissioned focus groups with people receiving residential care in different parts of the county. As mentioned above, there is a possibility that responses that we received in homes could be more positive than we might receive if people spoke to us outside homes. To try to ensure that we were not missing any negative feedback about the sector through the visit programme, we commissioned Opening Doors, a user-led advocacy organisation for people with learning disabilities. They organised focus groups in Cromer, Great Yarmouth, Norwich and Diss, made up of members of their weekly advocacy groups. They also organised a focus group in a medium-secure inpatient unit.

In these sessions, people were asked questions about their overall levels of satisfaction with their care, the top two things they like and dislike about their care, questions about staff, friendships, activities, and the support they receive to look after their health. Accessible visual materials were provided, and people were given support to record their answers to the questions where necessary. They were also given support after the session if they had found any part of the sharing emotionally difficult.

Overview of feedback received

As mentioned above, we carried out Enter and View visits to 25 services in total, including 21 residential homes and four in-patient units. There are currently (as of 31st May 2023) 113 residential units in Norfolk registered with the CQC and caring for adults with learning disabilities and/or autism, meaning that we visited around 19 per cent of the total. There are five in-patient units looking after people with learning disabilities and autistic people in Norfolk. During these visits we received feedback from 94 service users.

We carried out in-depth interviews with 58 family members. 46 of these we contacted with the help of the residential homes and in-patient units, and 12 were contacted through other means.

The focus groups run by Opening Doors were attended by 42 people in total. These people were living in a range of different settings, with 22 either currently or formerly in residential care, 3 currently in a secure unit, and others living in a mixture of supported living, living in their own homes, and living with their families.

The sections in the rest of the report reflect the main themes that people spoke to us about, or which came up in observations, and summaries of the feedback on particular themes can be found under the relevant headings. Here, we provide some detail on the overall levels of satisfaction that people reported to us, and how they varied between different sources of data.

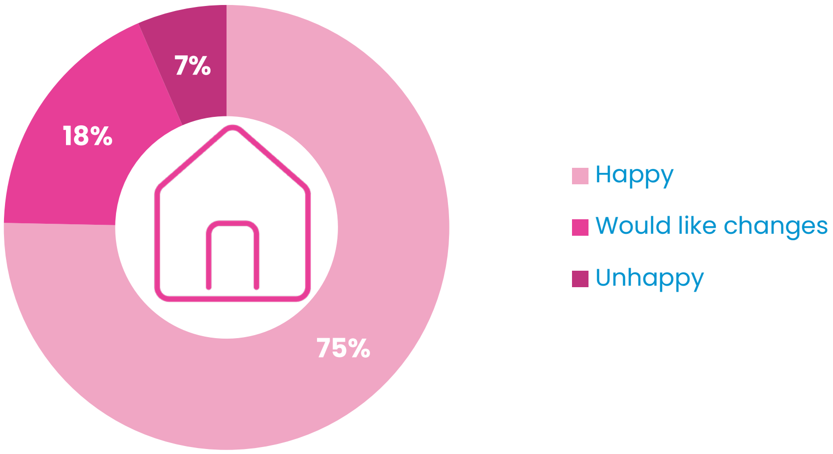


Figure 1. Overall levels of satisfaction with residential services from visit data and subsequent interviews with relatives.

As the chart above shows, most people living in homes, and their relatives, were happy with the care that they were receiving, with three quarters of people reporting that they were satisfied. A significant minority, 18 per cent of people, told us that they were generally satisfied, but would like to see some changes. 7 per cent of people were unhappy, to the extent that they wanted to go and live somewhere else. In the following chart, we show the levels of satisfaction reported by people living in residential care, who participated in the Opening Doors focus groups:

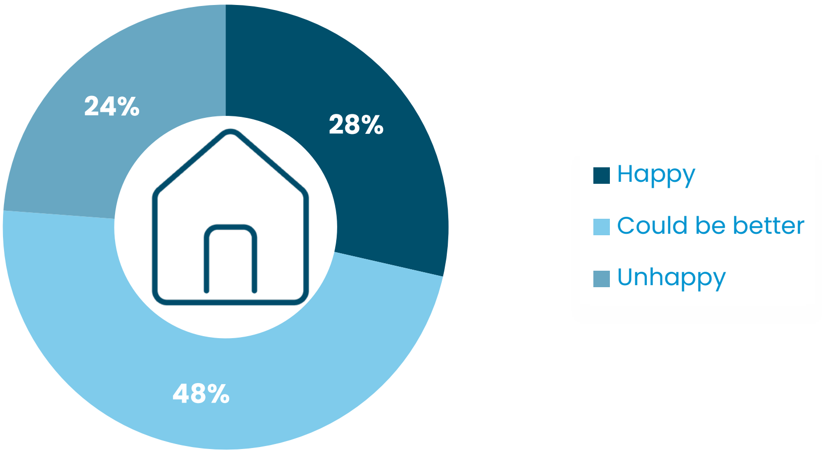


Figure 2. Focus group responses to the question, "How does it make you feel living in residential care?"

People living in residential care who participated in the Opening Doors focus groups reported being significantly less happy than the people we spoke to on visits to residential homes. Approximately half of people wanted to see changes (10 of 21, 48 per cent), with around a quarter saying they were happy (6 people, or 28 per cent) and a quarter saying they were unhappy (5 people, or 24 per cent). Similarly, the relatives who we interviewed who were unconnected to our home visits, tended to be less positive about the care that their relatives were receiving, with 5 out of 12 people being unhappy.

Since none of these samples is randomly selected, it is difficult to say which of these levels of satisfaction is the most representative of the whole population of people living in residential homes and in-patient units in Norwich. It is likely that the people who choose to attend Opening Doors advocacy groups are more unhappy than the 'average' resident or inpatient (although many people also lack the capacity to attend these groups without support). On the other hand, it is possible that people in homes were more likely to give us positive feedback within earshot of staff, and that home managers were able to influence which residents we spoke to most. This could mean that we gained a more positive picture of people's experience than the everyday reality of the 'average' person.

Whatever the case may be, our approach has allowed us to capture a broad range of different experiences in residential care and in-patient units in Norfolk, and a reliable picture of what most service users and their families view as good and bad practice in the sector. For example, in subsequent questions in the Opening Doors focus groups, people were asked to tell us the top two things they didn't like about their home, two things that they would like to change, and things that they did not like about their staff support. The most common subjects people spoke about were staff (either not enough staff support, that staff were not reliable, or were not kind), restriction of choices (such as when to go to bed, or when to get assistance with their personal care), choice of food, problems with the premises or local area, and that they would like to go on more outings. We cover all of these topics, and more, in the sections below.

Examples of negative feedback from the focus groups are on the next page.

Theme	Feedback
Staff	"No empathy for others". "Don't like staff letting me down". "Not having enough staff talk time".
Restriction of choices	"Them telling me when I can shower, I want to have a shower when I want not when they are free." "Being told when I had to eat. Being told when I had to go to bed."
Food	"They made residents use powdered milk and I didn't like it at all". "I would like to be involved in the meal plans".
Premises/area	"Don't like walking on winter icy weather and muddy paths". "Dining table chairs are too low and uncomfortable".

Outings	“I would like more staff to get out even more”. “I couldn’t go out for walks. And to the pub with other people.”

Views from professionals

Professionals' views of the residential and in-patient sector in Norfolk

To contextualise the feedback that we received from service users and their families, we started the project by gathering information from professionals in Norfolk about how they saw the state of the residential and in-patient sectors for people with learning disabilities and autistic people. We asked them for their views of how the sector has changed over recent years, how they view the state of the sector now, and what plans are in place for future improvements.

We spoke to 24 professionals from a range of organisations in the sector, aiming to cover representatives from social care services, health services, the third sector, and representatives of care providers. Our conversations therefore included people working for:

- Norfolk County Council
    - Integrated Quality Service
    - Learning disabilities commissioning
    - Adults and children's services learning and development
    - Adult social care workforce planning
- NHS organisations
    - Quality in Care Team – NHS Norfolk and Waveney Integrated Care System
    - Hertfordshire Partnership NHS Trust Learning Disability and Forensic Services Team
- Third sector organisations (Equal Lives, Opening Doors and About with Friends)
- Norfolk Care Association

We summarise the views of professionals from each of these organisations below.

Norfolk County Council

Integrated Quality Service

The Integrated Quality Service (IQS) brings together staff from Norfolk County Council (NCC) and Norfolk and Waveney Integrated Care System (ICS), and has a duty to promote diversity and quality in the provision of health and social care. They carry out inspections of care homes across Norfolk, and provide ongoing support to these services to improve the quality of care they deliver. The service was established in 2019, and is staffed by quality improvement officers and quality improvement nurses. The Head of IQS gave us his view of the state of the learning disabilities residential care sector in Norfolk, and informed us about recent changes to how the local authority works on quality in the sector.

He told us, as most professionals did, that the quality of residential care in Norfolk, in the LD sector and beyond, is lower than in most other areas of the country (as of April 2022, only 66.4 per cent of social care services in Norfolk were rated 'Good' or 'Outstanding' by the CQC, compared to 79.4 per cent in the East of England and 82.4 per cent in England). He told us that there are several factors that make delivering quality residential care in Norfolk challenging, related to the county's geography. Norfolk has a long coast, which makes it harder to recruit care staff from across county borders, because Norfolk has fewer neighbouring counties than landlocked counties do. In addition, many homes in Norfolk are in rural border areas that are relatively remote, which are hard to recruit to because people cannot travel to them very easily. This is particularly important because poor quality of care is often related to staff shortages, or the quality of leadership in services, which is related to the difficulty of recruiting good managers.

Other issues mentioned are related to how the residential sector has historically developed in Norfolk. Norfolk has a higher number of independent providers compared to other counties, where there are more providers who are part of larger provider chains. Chains can often offer support to each home in terms of human resources and recruitment, training, management and administration, which is not available to independent homes.

In addition, many services are in old housing stock. Although this is perhaps less of a problem in the LD market, where homes are aiming to be homely, such buildings are not purpose built. A related problem is that these older buildings are often in locations that are not ideal because they are far from towns where people can go for outings, meaning that more activities have to be provided in the home. Norfolk also has an unusually high number of people in residential care who have been sent here by other local authorities. This is a problem because it is more difficult for these people's local authorities to oversee their care from a distance, and also reduces the amount of capacity in the county for people from Norfolk.

IQS is making a concerted effort to improve the quality of care in Norfolk, and their role is detailed in a recently published Improvement and Escalation Policy (https://www.norfolk.gov.uk/-/media/norfolk/downloads/business/supplying-ncc/assd-policy.pdf). Their quality improvement work has three different aspects. Firstly, they provide ongoing quality improvement support to homes, related to two different kinds of audit visits they carry out, PAMMS visits (Provider Assessment and Market Management Solution visits - similar to a CQC inspection) and quality monitoring visits (to follow up on agreed action plans and to make focused enquiries on areas of concern). Secondly, they feed into decisions about whether to commission new providers, by looking at the quality of service they are likely to provide. IQS have been rejecting some offers to open new LD residential services in Norfolk due to quality concerns.

Thirdly, they can take action where a provider consistently fails to meet quality standards up to and including terminating a service's contract. Prior to 2018, it was very unusual for a contract to be cancelled due to poor service, and there were some NCC-contracted providers who had never been compliant with quality standards. An effort has been made by IQS and NCC commissioning to change this in recent years, and IQS now sends information on quality to commissioners, and some providers have been closed down for persistent breaches of contract.

In the view of this interviewee, the residents from these closed services moved to much better settings that offered them more independent lives, as befitted their levels of capacity, and he hopes to see better quality providers being commissioned in future who can continue this trend.

Learning Disabilities Commissioning

We spoke to the Head of Social Care for adults with learning disabilities, a Commissioning Manager and Senior Commissioning Manager for learning disabilities at NCC. They told us that Norfolk has a higher proportion of residential beds for people with learning disabilities and autistic people compared to other similar local authorities, who tend to have a greater proportion of supported living placements than in Norfolk. We were told that the assumption in Norfolk has often been that residential care is best for everyone, and that some people, who could be more independent, have been deskilled by this. There is a move by NCC to try to shift this culture, and to encourage providers to think of residential care as a stage for some people, who can be encouraged to move on to a supported living setting, once they have been supported to develop the necessary skills.

The people we spoke to echoed the view from IQS that the residential sector in Norfolk is “not in a good place” in terms of quality. Beyond the issues mentioned by the Head of IQS, the quality problems were also said to be related to low expectations in Norfolk amongst both providers and service users, with a perception that people needed to be “wrapped up and kept safe” and that people do not feel able to ask for more than this. These expectations were said to be related to a history of low-quality residential services in Norfolk, with some services operating in Norfolk which would not be registered by the CQC under their current requirements for new services. We were told that some providers are likely to leave the market, and between the end of the Covid lockdowns and June 2022, 12 homes had been supported to close.

NCC commissioning have been carrying out a review process of everyone with learning disabilities and autism receiving residential care in Norfolk. This has been done on a provider-by-provider basis, to try to understand whether people are in settings which meet their needs, and identifying people who might want to move on to a different setting. Part of this exercise has also been about working with providers and being clear with them about where commissioning is headed in the next ten years, and about the requirements that providers will be expected to meet in the future. Some providers in old housing stock are choosing to leave the sector because they think they will not be able to become compliant with quality standards or fit in with NCC's ambitions.

To establish what these ambitions should be, NCC undertook a consultation exercise in 2020 and 2021 to try to understand what people’s families want from homes and housing for their relatives. Over 120 people attended workshops and nearly 600 people completed a questionnaire. The main points noted from this consultation, were that people wanted to be able to choose where they live, to be part of the local community, to feel safe in an area with good neighbours, and to be close to local amenities and public transport.

In trying to respond to these ambitions, NCC have identified a number of challenges in the county, in which demand currently exceeds supply. This demand is coming from the number of people with learning disabilities and autistic people living with ageing relatives, the number of people in hospital and secure in-patient services who will need to be discharged, and population growth. Particular shortfalls have been identified in the lack of capacity in the market to support people with complex needs, and risky and distressed behaviours (including those who need to transition from secure in-patient services into the community); a lack of short-term services to help people progress to more independent settings; and the lack of a distinctive offer for young people which meets their long-term needs.

In response to these challenges, NCC has developed three development priorities: increasing the provision of enablement services to help people transition to more independent settings, increasing provision of long-term supported living settings, and increasing supported living places for people with complex needs. The latter can be particularly challenging to develop, due to the specialised nature of the buildings required, meaning that they are more expensive to build and less likely to be financially viable for developers. NCC estimates that 248 additional placements are required for supported living community housing, supported living for enablement, and mainstream housing close to enablement schemes.

NCC has made up to £18 million capital available to support meeting demand through the Specialist Housing Programme, which was initiated in March 2021. Three bespoke homes were completed in 2022, and a further 12 specialist properties to be completed ready for move-ins in 2023. A further 16 specialist homes are currently in progress, together with plans for over 60 homes to be delivered in over the next two years.

Adults and children's services learning and development

An important part of NCC's learning and development work with residential care providers recently has been the provision of training in Positive Behaviour Support (PBS), and we spoke to the Learning and Development Consultant who is co-ordinating this work. PBS is a person-centred approach to supporting people with learning disabilities and autistic people to improve their quality of life, in situations where they might struggle to manage their behaviour. It focuses on trying to understand why behaviours that challenge arise, by looking at the social, physical and individual context in which the behaviour occurs.

PBS has been growing in popularity across the sector in recent years, as a way to constructively deal with behavioural problems by understanding their root causes, rather than by resorting to medication or physical restraint. It seeks to identify potential behavioural problems early, to stop them escalating unnecessarily, and could be a key part of keeping people out of secure in-patient services. Once someone's behaviour has been understood, a plan will be developed with the person, based on their likes and dislikes, to help them to improve their quality of life and to develop the skills to become more independent.

NCC has been offering free PBS training to the staff of all NCC-supported care providers, free of charge. Different levels of training are offered, from a half-day 'PBS aware' training for non-contact staff, up to nine and a half days of training for the 'PBS informed' train the trainer course. Some of this training is quite intensive, and so NCC is trying to target staff members who have the power to change their organisation, and who are likely to remain with their organisation over the long term. As of April 2023, the CQC requires staff in LD residential care providers to have undergone PBS training.

There are some difficulties in rolling out this training, because some smaller providers who struggle to provide safe staffing levels, are not always able to spare staff for long enough for them to undertake the training. If an organisation can send one person on the train the trainer course, then this person can deliver the training within the provider, in smaller chunks as suits people's work schedules.

It is also worth noting here that, under the Health and Care Act 2022, it is now mandatory for regulated service providers to ensure that their staff receive learning disability and autism training appropriate to their role. The Oliver McGowan Mandatory Training on Learning Disability and Autism (https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism) is the government's preferred training for health and social care staff.

Adult social care workforce strategy

Given the problems with recruiting care staff identified by other professionals above, we also spoke to an External Workforce Manager at NCC. She mentioned similar recruitment problems as other professionals, including the levels of rurality in the county, but also identified some additional problems. There is no current national strategy for the social care workforce, as there is in the NHS Long-Term plan. We were told that this makes it more difficult for local authorities to plan, because there is no national strategy for them to "build underneath" in a way that is integrated with other areas. Recruitment in the care sector was also said to be made more difficult by the lack of parity with the health sector, in terms of salary levels, terms and conditions, and clear career pathways which would encourage people to stay in the sector long-term. This means that people will be more likely to choose a career in the health sector, where they might feel more valued, or a less demanding job than social care, which might be better remunerated, for example in the retail sector.

A number of measures are being taken by NCC to try to mitigate these problems. They have set up the Norfolk Care Careers website (https://www.norfolkcarecareers.co.uk/) which gives advice and encouragement to get involved in social care work, and lists vacancies in the county. Social care careers are also advertised through adverts on TV, social media and mobile adverts. Support is provided for free training, through Norfolk Care Academies, set up with Norfolk and Suffolk Care Support, which provides people with free social care training, and arranges interviews for them with provider organisations. Incentive payments are also given by NCC to providers to pass onto new recruits, once they have been in post for six weeks, and wellbeing support is offered for care workers. NCC also runs workshops for providers to provide advice on how to recruit and retain staff.

Support is also provided for international recruitment, including building a community of practice around international recruitment, so that providers can share expertise in this area, which many find daunting. Support is also given to the Integrated Care Board's international recruitment hub, including sending CVs to providers and doing checks for them, so that the provider can focus on interviews and selection. This support also includes trying to get parity with health in the overall packages people are offered to come to the UK, for example providing money towards flight costs, airport transfers, grocery deliveries in their first week, pastoral support and driving lessons.

NHS organisations

Physical health in residential homes

We spoke to a Senior Nurse for Learning Disability Quality, who regularly visits residential homes looking after people with learning disabilities, to get her view on how people's health is being looked after in homes. She told us that there had been some recent improvements in how people's health is being looked after. There is more oversight of people's health than there used to be, and the health of people with learning disabilities and autistic people is no longer viewed as a second-class issue.

However, several problems remain. One is around care staff and their understanding of capacity to make decisions around health, which could be very 'black and white'. We were told that staff sometimes tell health professionals that, for example, someone has chosen to eat fatty or sugary foods despite having diabetes, and that they should be free to make this choice. However, on closer questioning, it would often emerge that no-one had explained to the person what the consequences of eating these foods would be for them, meaning that they had not been able to make a fully informed decision.

In this person's view, these sorts of practices were contributing to health problems for people in homes, particularly related to diet, toileting and constipation, and respiratory problems. People are sometimes considered to 'have capacity' to manage these issues themselves, but are not being given the support they need to do so successfully. This is partly related to a lack of skills in homes, which is in turn related to levels of staff turnover, and many homes having influxes of inexperienced staff who do not yet understand the Mental Capacity Act.

Everyone with learning disabilities and autistic people is supposed to undertake an Annual Health Check with their GP, to try to catch any health problems before they become serious. This became more difficult during the pandemic, and health check rates dropped to 40 per cent. As of June 2022, this rate had risen to 70 per cent, which is the national target, though the ambition in Norfolk is to achieve 100 per cent. Many of those who did not have a health check had declined to have one, but it is not always clear who has declined on whose behalf, and whether they made a fully informed decision to do so.

The ICS is also aiming to improve the quality of health checks, and is aiming to have an LD champion in every surgery in Norfolk. There are regular online meetings for LD champions, and regular sharing of all the 'gold standard' health check procedures, because, we were told, there is some variation in how much depth health checks have gone into.

Hertfordshire Partnership NHS Trust Learning Disability and Forensic Services Team

The Hertfordshire Partnership NHS Trust runs Norfolk's only medium-secure unit for people with disabilities and autism in Norfolk, as well as the only Assessment and Treatment Unit, a Learning Disability and Forensic Services Team and an Enhanced Assessment and Treatment Service. The latter two services provide a bridge between in-patient units and the community, providing support for people before and after they are discharged from the services, and providing support for people who are at risk of admission.

The objective is to keep problems from snowballing so that people do not end up in secure units who do not need to be there. For forensic patients (people who are mentally unwell and who are in the criminal justice system), they try to provide people with safe pathways away from offending, which are envisioned to last one or two years. They use psychological therapies to help people and provide assistance with drug addiction. Their work often involves helping people with relapses in behaviour, to try to prevent people getting to the point where they need to be admitted again. The teams also provide training for people in community settings (including residential homes) where people are admitted from secure units, or where people are at risk of admission.

This training includes elements of PBS training, but also some more specialised training packages.

Professionals in the Learning Disability Forensic Services team thought that there has been progress in keeping people out of secure units since Winterbourne View, and that there is certainly a drive to make changes. However, they told us that there was still a problem with expertise in the settings that people were discharged into. People can end up in settings where the staff have no forensic training, or in settings where people have complex needs and lesser capacity, which are inappropriate for people with forensic histories, who often have mild learning disabilities. Their training packages are designed to try to tackle some of these problems.

Norfolk Care Association

The Norfolk Care Association (NorCA) represents social care providers in Norfolk and Waveney, and we spoke to a member of their board of directors. We were told that, over the past ten years since Winterbourne View, there have been some positive changes in how providers think about the values of the people that they employ. This has been influenced by the 6 Cs of care (care, compassion, courage, communication, commitment, competence), and providers have a better idea of what they are looking for in recruitment. The Care Certificate has also been established since Winterbourne View, and sets 15 minimum standards, which should form the induction programme for new care staff.

The person we spoke to also mentioned NCC's residential review project, and said that many providers were currently considering whether their buildings could accommodate the supported living model. However, providers were said to be keen for the cost implications of the proposed changes to be considered transparently. There were worries that the proposed numbers of people in each provider will need to be smaller, meaning costs are likely to be higher, and at the same time, in recent years there have been pressures to cut costs. We were told that many providers think that there needs to be an honest conversation about what the proposed best practice is likely to cost. It is worth noting in this respect that, at the time of writing, NCC was beginning a 'costs of care exercise' with LD residential care providers, to try to understand what the true costs of care currently are.

Another significant concern faced by providers is the difficulty of recruiting care staff. The person we spoke to told us that in their 30 years of working in social care, recruitment problems had never been so severe. Levels of pay for care staff are low, especially at entry level, and staff really struggle with the rising cost of living. There are also high levels of responsibility in care work. This means that jobs that have similar or higher levels of pay, but lower levels of responsibility are more attractive for many people. In addition, recruiting internationally is more difficult than it was in the past. International staff have left the sector since Brexit, and it is now harder to recruit people to come to the UK.

Moreover, as mentioned above, there was said to be a disparity between the respect given to healthcare workers, and that given to care workers, and this was particularly clear during the pandemic. There was a clap for NHS workers, but not for care workers, and workers in hospitals were protected more rigorously than those in care settings, where there were delays in testing at the beginning of the pandemic. There is also less of a sense that there is a career path for care workers, compared to healthcare, and a general sense that you will not be treated as well.

Third sector organisations

We spoke to people from three third sector organisations, Equal Lives, a disability organisation based in Norfolk and Suffolk; Opening Doors, a user-led advocacy organisation for people with learning disabilities based in Norfolk; and About with Friends, a learning disabilities charity based in north Norfolk promoting the independence of people with learning disabilities, and running supported living services, a café, day service and work skills programme.

These people had a critical view of the state of the residential and in-patient services sector in Norfolk for people with learning disabilities and autistic people. They agreed with other professionals that we spoke to on some issues, particularly about the need to move away from such a high proportion of residential care places, the need to improve the quality of residential care and the impact of staff shortages on the sector.

However, they also told us of several cases that they had come across of people who wanted to move to a different residential placement, but who had not been able to. People who they were in contact with had experiences of annual reviews with social workers, where there were considerable barriers to finding a placement that they were happy with, or that was suitable for their needs. These barriers included that people were offered placements away from their relatives and friends; that someone was given a placement with a far higher degree of support than they needed or wanted, with the result that they became de-skilled; and people being sent to placements with co-residents who were very different from them.

They also raised several problems with how they had seen annual reviews working with people who used their services. One person believed annual reviews with social workers should not take place inside residential homes with staff present, but should happen at a neutral venue, where people were more likely to feel able to raise concerns. Another person told us that some of their members had not had annual reviews for a long time, and that they were often carried out by Assistant Practitioners, who they thought were not sufficiently knowledgeable to carry them out properly. One person raised the issue that, in the past ten years, people have stopped being allocated to the case load of one social worker, and now have their annual review done by someone they have never met before, who they may not know how to communicate with, and who they may not fully trust.

Feedback from service users and their families

Shortages of suitable care placements and the difficulty of transitions

Much of this report will focus on what people told us about choice, independence and quality of care within homes and secure wards, but this has to be considered alongside broader systemic issues. An important problem that some families and service users told us they experienced was the shortage of what they considered good quality residential provision in Norfolk, and/or of suitable placements for their specific needs. In some cases, this meant that people's choices were considerably constrained. Nine relatives told us about these shortages, and most providers and professionals acknowledged that it is a key problem for the sector in Norfolk.

There were a number of reasons that people had difficulties finding a placement that was right for them. For some people it was a question of finding a service that could meet quite specific sets of needs. For example, one person told us how their relative has quite severe autism, which means that they need specialist care to successfully meet their needs and help them to manage their behaviour. On the other hand, part of their condition is that they had a low tolerance for people with similar behaviours to their own, so they need a placement which both has the specialist expertise, and yet cares for few people like them. The relative describes this as like "trying to thread a needle".

For other people, the problem was a social one. Some people told us that they had been offered a placement that could meet their needs, except that it was far away from their friends and family. Clearly, for people with trouble travelling independently, this would be a significant blow to their ability to maintain the relationships that were important for them. As one relative told us:

> "It's not acceptable to say to a young person, 'You're moving house, but you cannot go to your day centre and see your friends anymore because you've moved house.' That wouldn't be acceptable for you or I."

Some providers and some relatives told us that finding support for people with distressed behaviour could be particularly challenging. Two managers told us about times when someone's behaviour became too difficult to manage, and put other residents at risk. The managers served these people 'notice to quit', meaning that they would need to find a new placement and leave the home. However, due to a shortage of suitable placements for them to move to, they were left living in an unsuitable placement for a long period, over a year in one case. This clearly has significant negative consequences for the people who have been served notice to quit: they were both unhappy in their placement and wanted to move out, and needed a placement that could help them to manage their behaviour better.

For other families we spoke to, they had a more general sense that they could not find care of sufficient quality for their relatives in Norfolk. Three families told us that they had made the difficult decision to send their relative to a placement outside Norfolk, where care was better personalised, and encouraged people's independence more than the homes that they had seen in Norfolk.

These shortages had some significant impacts on the wellbeing of people and their families. A particular issue that we found was the transition from young people's services to adult services. Seven families we spoke to told us that they had been unable to find a suitable placement in Norfolk, and for five of these families, this meant that they had young adults living at home. Although some of these families had help from domiciliary carers, meeting the needs of their young people put families under extreme strain. This was particularly severe for one-parent families. The young people themselves were frustrated not to be able to move out of their parents' home once they had become adults, particularly when they had seen siblings without disabilities move out. This frustration could make their behaviour more difficult to manage for their families.

While services supporting the transition from child to adult services seem to have improved in recent years with the establishment of the Preparing for Adult Life (PfAL) team, people still reported significant problems with the transition. One parent, whose daughter had been waiting five years for a suitable placement, told us,

> "What is really sad is that the statutory bodies must have information about young people who have been through school. They've left school. They've had this transition thing. And they must now work out how many

young people are going to need supported living or residential … It was an absolute disaster for us. The transition was-- it's a work of fiction. You have these meetings. And the young people hit 18 and children's services stop and adult services is supposed to kick in, and it just doesn't. It didn't for us. It was an absolute nightmare.”

It should be noted that this parent’s daughter turned 18 before the PfAL team was established. However, another parent told us that while they were happy with the support that PfAL provided, the team came up against a shortage of care that they were unable to remedy: “PfAL could totally understand the pressures in the situation we were in. They were really fighting our side. But there just wasn't any resources available.”

Parents who had sent their children as young adults to placements outside Norfolk told us that they were worried about what they would do when they became too old to travel to visit their relatives. They faced a choice between being cut off from regular face-to-face contact with them, or what they saw as the daunting task of trying to find them a suitable placement in Norfolk.

People who had found a suitable placement for their relative in Norfolk, quite often had a story of their relative moving from placement to placement which were unable to properly meet their needs, often spending years of their life in unsuitable homes, before they found the right one. As one mother said of her son, “I feel I'm very lucky at last to have found the right place. But I'm very sad for him that it's taken so long.”

We came across fewer people who were making the transition to care settings for older people. Where people’s needs had increased as they aged and developed new conditions in some cases, we found that homes had made adjustments so that they could continue to care for the person in their existing home. However, in one home we found that two people with learning disabilities had been moved on from their specialist LD home to an older people’s home due to their increased needs. Here, they had much less choice in terms of activities that they could undertake, and spoke fondly of their former home.

Recommendations

- Norfolk needs to develop more specialist placements for people with learning disabilities and autistic people, in all areas of the county, particularly to provide places more promptly for young people when they become adults.

- As people age and their support requirements change, steps should be taken to ensure that they are able to remain active and stimulated if they need to move home.

Personal story: “Exhaustion is my default setting at the moment”

“So, the thing is as parents, you move heaven and earth for your kids, really. I managed to get a job through just fluke, really. It was being in the right place at the right time. They offered me a job and I said I couldn't do it because it didn't meet with my daughter’s needs. So, they asked me what hours I wanted to do. And basically, they gave me the hours that I wanted. So, I get my daughter on transport. I go to work. I do my five and quarter hours, and I get home just before my daughter gets home. And if there's traffic or if I'm delayed leaving work, it's like constantly spinning plates. And anytime the plate could fall off, but we make it work. We make it work but it is hard work.

And the other issue is the lack of properly trained carers. Carers are underpaid and undervalued. It's a really highly skilled job. And they're leaving because they can get better pay in supermarkets, and that is absolutely shocking. So, we've had one carer for several years who's absolutely brilliant. We can't fault her at all. And we had another lovely carer who left recently. So, we're down on carers as well. So, I'm just exhausted. Exhausted is my default setting at the moment”

- A mother of a young adult waiting for a care placement.

Listening and not listening to residents

As mentioned in the introduction, one of our key research questions was to find out whether and how service users and their families were being listened to, and to identify problems, and examples of best practice in this area.

During our Enter and View programme we heard that around half of the settings visited held regular residents' meetings. Staff most often told us that these were used to discuss activities that people wanted to do, menu options, and any changes that people would like to make or issues that they were unhappy about. These meetings varied in frequency, with most settings holding them once a month, but some holding them on a weekly basis.

Where meetings were not used, staff gave us various reasons for this. In two homes we visited, we were told that they were trying to promote a more family-like atmosphere in the home, and used other formats to gather people's views. One provider preferred to use mealtimes as an opportunity to discuss house matters in a way that was more informal and hopefully made people feel more relaxed. Another told us that the manager would schedule a weekly cup of tea and a chat with each person, making sure that the results were documented and acted upon, as well as trying to discuss things at mealtimes. At seven providers, staff explained that they found residents' meetings were not productive ways to consult people due to the nature of their conditions, for example if all, or almost all, people were non-verbal. These providers preferred to use more individualised ways of consulting people, usually through regular one to one keyworker meetings. There was one provider with all non-verbal residents who did have regular residents' meetings, with keyworkers helping people to communicate.

In addition to more formalised listening mechanisms, an important part of how staff listen to residents is of course through how they interact with them on a day-to-day basis. We discuss this issue in more detail in the section on staff, below.

In the 11 residential settings that we visited where people were able to talk to us, they told us that they were happy with how staff listened to them. They would often give us examples of how staff did this in practice. For some people this was demonstrated in how staff would listen to their preferences and help them to pursue their hobbies. For others, it was more related to having staff available to chat to them throughout the day, so that they would not feel lonely. In the minority of cases where people told us that they did not always feel listened to, staff told us that this was related to balancing risk and best interest against people’s preferences. For example, one person wanted to be able to cook with heat, but was not being allowed to because when this had been tried in the past they had often forgotten that they had left the hob on, posing a fire risk. Some of these cases seemed to us to be debatable, though we were told that they were based on risk assessments.

In the remaining residential settings that we visited where people were not able to speak to us, we observed that staff were generally able to pick up on non-verbal cues and sign language to understand what people were communicating, and were able to tell us in some detail about how they could understand people. We were able to witness visual cues ourselves that indicated whether people were happy while communicating with staff, and they were sometimes able to answer yes and no questions about whether staff listened to them – and usually indicated ‘yes’.

The data from our focus groups outside the homes gave a more mixed picture. Seven people (out of 22), when asked what their favourite things were about their home, mentioned staff listening and responding to their requests were what they most valued. Two of these people mentioned that staff were willing to listen, but were sometimes too busy. Five people, when asked what they least liked about their support, and what they would like to change, mentioned problems with not being listened to by their staff. One person mentioned a general lack of empathy from staff, two people mentioned a lack of choice around when things happened (one person around when they eat, and the other around when they shower), and another person mentioned that staff did not have enough time to talk to them and keep them company.

Two people mentioned that some staff members English was ‘not great’, which made it hard to communicate with them. Two other people made the same point when they spoke to us in other settings. Whilst this is concerning in these individual cases, given the number of care staff who have English as a second language and the number of people we spoke to overall, these numbers do not seem concerning in terms of our overall findings.

The interviews with relatives gave a generally positive picture around how residents are listened to in homes. Some of the relatives that we interviewed independently of contact with homes were more critical in this respect, and reported instances of their family members not being listened to.

One person told us that their relative had not been listened to by staff over a long period of time, and now seemed to have given up trying to express their views, “now, he will say very little. If you said, "Do you like living at [this home]?" he'd say, “Yes. Pleasant, very pleasant.” … I think some of it is he probably feels he doesn't have any agency. If he says things, nothing happens.”

Another person told us that their relative was made to feel that their views were not important: “You should have what you want in your home. But, I know from a lot of what we've talked about before, that doesn't, that's not the reality that he's experiencing … whether that's people just being dismissive or not paying attention to, to what he says. Often, he gets shut down”.

A third person told us that staff did not always communicate with their relative in a way they could understand: “They were saying about advocacy … but he doesn't understand what the word advocacy means. There was no tailoring to an appropriate level. I'm not saying patronise someone, but recognise the language they need.”

The interviews with people who we contacted through the homes were almost universally positive about how homes listened to their relatives. 26 relatives told us that they were happy with how staff listened to their family members, and were satisfied that staff understood their needs and aspirations:

Some positive comments on listening:

- “They always consult [my relative] and they do this with everyone. Before they do anything with the residents. Sometimes people can disregard people with disabilities, but they don't do that there”.
- “You like to think that you know your relatives, but [the manager] sees things that I don’t see”.
- “[My relative] considers the staff to be her friends, and the staff understand her well. They know how to communicate with her, and know the things that she doesn't like”.

Five relatives did identify some problems related to staff shortages and communication. Four people mentioned how high staff turnover can make things difficult for their non-verbal family members, because it takes a long time to understand how they communicate. A fifth person mentioned, that, while they were very happy with their family member’s keyworker, on shifts where the keyworker was not present, problems could sometimes arise. These issues are discussed in more detail in the section on staff, below.

Personal story: Listening and responsiveness

"He has gone through a phase now where he would like a Christmas tree in August. So, they phoned us and they said, 'Oh, Mr. and Mrs. [name], just to let you know that your son is adamant that it's Christmas or that he needs a tree now. He's going, 'Christmas, Christmas tree'. So, we've bought a very small one and occasionally, in the summer, there'll be a small Christmas tree with a few lights on, and if that's what he really thinks, whatever, he also likes Christmas in December. So, to answer your question, they seem to have a very close understanding of how he is, what motivates him, and what he doesn't like."

People's relations with care staff

For the people in the homes we visited, relationships with care staff were often some of the most significant ones in their lives, and a central determinant of the quality of care that they received. Most of the feedback we received about staff, and the observations that we made, were positive. Where there had been cases of poor practice, people were satisfied at how providers had responded to these. A consistent area of concern identified by family members, was the high turnover of staff in some settings, and how this affected the care their relatives received.

Predominantly positive relations with staff

The verbal responses we received during Enter and View visits, suggested that most residents were happy with their support staff, and our observations supported this impression. A large majority of the people that we spoke to in the homes we visited told us that they liked the staff, and that staff listened to them and looked after them well. When we asked people what they would like to be different about their staff support, most people told us that they did not have anything they would currently like to change.

This positive picture was supported by the interactions that we witnessed between staff and residents. We almost always saw staff interacting with people in a respectful and caring manner, staff seemed to know their clients well and knew how to meet their needs.

How these relations played out partly depended on the level of support that people needed. In homes with higher levels of support, we saw more intensive interactions between staff and the people they supported. In the case of caring for non-verbal people, we usually saw staff responding promptly to non-verbal cues, and they would often pick up on quite subtle signs that someone was becoming overwhelmed or anxious. Where we did witness incidents of people becoming upset, staff were skilled in calming people down. The keyworkers we spoke to were able to explain to us in some detail how they knew what the person they were caring for wanted, and how they responded to these cues. Most staff were also careful to involve people in conversations about them, whether they could speak to us or not. In most settings, staff sought people's consent before providing care or entering their bedroom, although in a handful of settings, staff offered to show us people's bedrooms without asking them first.

We usually saw staff sharing jokes with residents and taking the time to chat with them. People who could, often told us of the activities that staff had helped them to undertake, and we often witnessed these first-hand. They also told us about the tasks which staff helped them to complete, and would often mention when staff took good care of them.

Sometimes residents and relations would talk about staff as being like a second family, and the homes which were best at advancing people's voices and responding to them, seemed to have more non-hierarchical and reciprocal relationships between staff and residents. For example, relationships seemed to be strongest where residents knew a lot about the lives of staff, so that they related to them as more than just professionals doing a job. One home had a display on the wall, which gave information about aspects of residents' backgrounds, likes and dislikes that they wanted people to know about – but it also gave similar details about staff. In another home, people would often bump into family members of a staff member who lived locally, and seemed very appreciative of this, given that this staff member also knew their families. Residents clearly enjoyed relationships where they knew their staff well, and had shared interests that they could enjoy together. These tended to be particularly strong in cases where they had known their support staff for a long time, and had shared memories of good times together.

Where people expressed some reservations about their staff, it was usually because of some areas of disagreement, where staff were trying to strike a balance between acting in residents' best interests, and giving them control over their lives. Sometimes this was related to diet, with staff trying, for example, to encourage someone to eat more healthily because they were borderline diabetic, while respecting the right of someone to choose to eat foods that could exacerbate the condition. Where such cases arose, we were usually able to establish that residents were reluctantly responding to the encouragement of staff to change their diet, and not being prevented from taking informed unwise choices.

The participants from the focus groups outside homes gave a number of aspects of staff support that they particularly valued. The most common were, staff listening and being helpful (seven people out of 22), going on outings with them (five people), and making them feel happy when they are down (three people). Aspects that some people were unhappy with were when staff would not let them do what they wanted (five people), for example showering and going to bed when they wanted to, and when staff did not support them reliably (three people). Overall, there was a positive opinion of relations with staff in these focus groups, with ten people counting staff as their friends, against four people who said they were not their friends.

The views we gathered from relatives supported this positive view overall. 29 interviewees were happy with their relative’s support staff in their home, with seven having more mixed views about them. Common themes in the interviews were how much relatives valued staff who knew their family members well. Several common reasons were given for this. Firstly, because they considered that it is important for communication purposes, because for some people with communication difficulties, it took time to get used to their particular ways of communicating. Secondly, and again relating to people with communication difficulties, it took time to understand people’s habits and preferences, and how to keep them happy. This seemed to be especially important, when staff were trying to allow people autonomy, while managing difficult behaviours. As one person put it, “the staff work really hard to match what he wants with what is sensible for him … it’s a very difficult balancing act with [him].”

Perhaps the most important reason that relatives put forward for this, was because they were reassured that their family member was happy, and enjoying family-like relationships, if they had support staff who knew them well. Some typical quotes on this theme include: “She [his support worker] is his favourite person in the world, even more than her father”, “they’re like his family there”, “I think they do love him”.

Trust was also an important theme. It was often a difficult decision for families to give their relatives over to the care of strangers, and establishing trust was important. Some relatives had had bad experiences of care in the past, and some expressed relief that they seemed to have finally found a home with staff they could trust. As one person put it, “most of the staff I would trust with my house key and my purse”.

Where people had more mixed views about the quality of staff, it was mostly because the quality of staff could be variable. As one person put it, “there are good carers and there are bad carers. There are some of them who will go to great lengths to involve them and others who … just want to get on and get it done”. There was a recognition from some people that, while many staff felt a vocation for care work, there were some who did not. For some others, the mixed quality of care was due to the fact that their relative got on particularly well with one staff member, usually their keyworker, but struggled more on shifts when they were not present, or if they woke up at night and were faced with a staff member who did not know them well. The reverse situation, where several members of staff know someone well was particularly appreciated. As one person told us, “If I turn up at the door to talk to him - I can ask any member of staff, and they will all know how he's doing in some detail. I don't have to wade through treacle."

STAFF RESIDENT RELATIONSHIPS

WHAT PEOPLE VALUE MOST

1) RECIPROCAL AND NON-HIERARCHICAL RELATIONSHIPS

People liked to have shared interests with staff and to know about their lives. They also liked to be treated as equals.

---

2) LONG-TERM RELATIONSHIPS

People preferred to have the same staff for a long time so that they could develop quality relationships with them.

3) FAMILY-LIKE RELATIONSHIPS WITH STAFF

People were most happy with affectionate and trusting relationships that were similar to family ties.

---

4) STAFF WHO KNOW RESIDENTS WELL

This was particularly important for people with communication difficulties, who had trouble communicating their wishes and personality to people they didn't know well.

The impact of staff turnover and staff shortages on people’s quality of life

Given the importance placed on staff knowing the people they support well, and the time it can take to achieve this, it is not surprising that in situations of high staff turnover, people were less happy with the support being provided. Residents we spoke to would mention that they had found it difficult when staff changed, particularly given how close these relationships could be. This could be confusing and disconcerting for some people. As one relative told us,

> “I think he doesn't really understand why there are sometimes support workers and [whether they] are his new family. I think the whole thing has been quite difficult for him to grasp. And because he's had negative experiences and he communicates less, it's been harder to try to talk that through. And there are times when there's lots of staff movement, and when I meet him, he's in what I would call survival mode and it's like you almost can't reach him because his life is not settled and safe enough.”

As relatives told us, some people took a long time to adjust to new people, and would react badly to changes in staff. One person remarked of their family member’s home, “They cannot get staff. So, you get staff going in there who don't know the ways and where, I mean, [my relative’s] always been a person, if they get a new member of staff and she takes an instant dislike to them, she, she sort of won't go near them.”

For people with communication difficulties, frequent changes of staff could have a strong negative impact on people’s ability to control how they are cared for, and to have their voices heard and understood. As one relative put it, “When you bring in agency staff, they just won't be able to understand her. It will take a long time for them to get to know her, because she has complex needs. This makes it much harder for her to have control over her care, because they can't understand what she wants.”

Relatives also found staff turnover difficult, if they had spent some time explaining to staff how they wanted their relative to be cared for, they then had to explain all over again to a new person. For example, one relative told us, “We bought tubs and we bought compost … And that year, it was all good, wasn't it? And we've taken plants over, haven't we? But this year, it's been the worst year for that sort of thing because his one-to-one had left. So, we have got a lady picking up his one-to-one, which was very kind of her, but she's a bit like, "Oh, I've done it.

It's all done. I've done it." And then when you go over there, it's all sad in the garden.”

The family members that we spoke to were often keen to point out that they understood that staff shortages are a national problem, and did not see this a problem that was particular to their providers or to Norfolk. Nevertheless, it seems to be having a significant negative impact on people’s quality of life.

High staff turnover was people’s biggest staff-related concern

It had negative impacts on:

- The stability of trusting relationships that are vital to people’s wellbeing.
- People’s ability to communicate with their support staff and so to have their voices heard.
- Relatives’ ability to have an input into their family member’s care.

Managers

Managers are often the key point of contact for relatives of people living in care homes, and for making sure that feedback is acted upon. We also observed that most managers knew the residents of their care home well, and interacted cordially with them. While people living in care homes did not mention the manager often (although we did observe interactions with them), managers were often mentioned by family members in both good and bad lights. The main themes that emerged here were, the impact of high manager turnover, the importance of managers who knew and understood people well, and the importance of frank communication and open discussions. Responsiveness and listening were also important themes, but these are covered in the section, 'Listening to family members'.

High manager turnover

In the homes that we visited where relatives had recently had serious concerns, this tended to be because there had been a change of manager, or several changes of manager in a short space of time. Changes of manager were seen as having knock-on effects on care staff in the home, which affected both communications with families, and staff morale and retention. Where changes of manager were handled smoothly, they were not necessarily a problem, and when there had been a recent change, people were not concerned about it. Sometimes this could be because a senior staff member they already knew was promoted to the manager position, which was not unusual, and in the case of one home it was because the assistant manager had provided stability as an interim manager.

However, in two homes where there was a more disruptive change of manager, and several managers appointed and then leaving in a short space of time, family members were more worried. As one of them told us:

> "We have been through a rather black period last year when I think we got through five managers in half a year … I found that disruptive, and it was very difficult to have good communication with staff … I'm hoping that the new manager will stay longer than her predecessors. [the old manager] was there for more than a decade, and we got on really, really well. I think there's an opportunity for a similar relationship with [the new manager and her deputy]."

In this home, care staff also told us of the impact on them of multiple changes of manager, saying that each manager would bring in a new approach to running the care home, the staff would adopt to a new way of working, and then the manager would leave. This affected staff morale, and in two homes we visited, they told us that staff had left due to this kind of instability.

Importance of well-informed and engaged managers

When relatives praised the manager of their family member's home, they would often tell us that the manager there knew the residents and staff well, and was engaged in the day-to-day life of the home. They would use phrases such as "clued-in", "clued-up" and "on the ball" to describe them. This seemed to be related to relatives valuing managers who care enough to engage meaningfully with residents, and to take a personal interest in their care, rather than dealing only with organisational issues. People would praise managers' compassion and caring attitudes. As one satisfied family member put it, "[the managers] have a gift for compassion, care and knowledge in combination."

When the manager was not engaged, relatives were often particularly unsatisfied. As one person told us: "There were many days [the manager] didn't appear. Or did short days. She didn't go to see [my relative] … Spent an awful lot of time eating cake with the other girls in the kitchen." A lack of engagement was said by another relative to lead to breakdowns in communication between managers and staff, with knock-on effects for people's care.

> "The difference between talking to someone quite high up and I am to then talking to the support workers is vastly different. I'm told, oh, well this should have happened, and this should have happened and this should be in place, and then I go to the support workers and they go, 'what are they talking about?' … I think it's, uh, this kind of ivory tower issue, if you've got management who aren't aware of what's happening … then that's where you've got that point of difference where change can't happen because the staff don't feel like they're being supported or listened to … So, it's very difficult talking to the staff around the current crisis [that my relative is having]."

Importance of frank and honest communication with relatives

The feedback we heard from relatives suggests that relations with managers can be difficult to handle. This is because it was inevitable that sometimes problems would arise with people's care, or incidents or accidents could happen. It was also because there could be differences of opinion between managers and relatives, for example when relatives had requests that the home was unable to fulfil. Our interviews suggest, however, that most relatives are aware of accept these problems, and that problems arise when managers shy away from these problems. In particular, open and honest communication was vital for maintaining relatives' trust in a home, and for managing disagreements constructively.

The importance of being open and honest about mistakes and incidents was often mentioned. When relatives were praising a manager they would often say, for example, "If there's a problem they will phone immediately". This both helped relatives to trust managers because they were confident that nothing was being hidden, but it also helped them to get involved in their relatives' care if they wanted to. One person told us, in the case of a disagreement between their relative and another resident,

> "[The home] is extremely honest. They told me about the disagreement, and I knew what the other resident had said. [His former] care home was very cagey about this. It's easy to talk to [his current home] because you know that they are telling the truth. And what they say makes sense, and they are talented and reasonable people. The honesty is quite striking - you've got the detail there to work with."

As this quote suggests, when managers were less honest, relatives start to lose trust. The same is true of when managers' statements did not match their actions. One person told us, "the worst managers know what to say, and then don't act". Another person said, of a good manager, "she's not one of those professionals (and you come across them in any profession) who know the theory but don't do the practice. She actually practices it." One person raised her worry that the manager of her son's care home was able to give a misleading impression to professionals, because this person knew how to present the home in a favourable, but inaccurate way. As she said, "the manager was very good at manipulating people and had quite a high standing amongst other professionals … the area manager too, would accept whatever the manager presented in terms of paperwork or, ‘Come to this house to see this fab thing that's happening,’” in the case of an isolated event that she thought was put on mainly for publicity purposes.

Frankness was also related in people’s accounts to the successful management of disagreements. When relatives told us about good managers, they were happy when they felt that they were being listened to and responded to when appropriate. When a difference of opinion did arise, they reported being happy to accept the manager’s point of view, if a convincing explanation was given. As one person said, “I'm not a fool, and if I felt something wasn't right, I would raise the issue, and the issue would be addressed. And if I was wrong, then they'd tell me so, and I'd say, ‘Well, sorry. I never thought about that.’ If I was right, they would make every effort to change it.”

Even when disagreements were less easy to resolve, relatives were happier if they were reassured that a manager had the best interests of them and their family member at heart. One person, who did not want their relative to receive a Covid vaccination, was much happier with a manager who took an empathetic approach to the situation, than a previous manager who tried to handle the situation behind her back. Another relative told us of a time when their relative was served ‘notice to quit’ by the home because of problems managing their behaviour. “They were all very collaborative and collegiate … everyone wanted what was best for [my relative], there was no conflict”.

In cases where disagreements became conflicts, this could have a seriously detrimental effect on relatives. We were told by several relatives that they feared being labelled “interfering relatives”, and so excluded from their family members’ lives. For example, one relative did not feel that she could try to persuade her son to move to what she saw as a better home, for fear of allegations that she was not acting in his best interests,

> “And I haven't moved him because he doesn't want to move. I've been incredibly fearful with the previous manager, and particularly the awful social worker, that if I said I wanted Jake moved, they would play the card of, ‘[he] doesn't want to move. His mum's not fit to be his attorney.’ And then I'd be out of his life.”

Best practice from the perspective of service users’ families

What mattered most to service users’ families in their interactions with managers was:

- Managers who were engaged in the everyday life of the home.
- Managers who knew and understood residents well.
- An approach to disagreements based on open communication, being receptive to suggestions, and clearly prioritising the best interests of the resident over other considerations.

Premises

The physical aspect of homes was of course one of the key areas for observation and conversation on our Enter and View visits, and could both reflect and facilitate people's control over their homes and their everyday lives within them. Feeling at home, or that a home was 'homely' was an important theme across the feedback that we received, and providers seemed to recognise this. Most home managers were trying, with varying degrees of success, to provide a homely environment for people. While homeliness meant different things to different people, common parts of most people's ideas were that you could shape your living space according to your own preferences and personality, and that you could feel safe, secure and cared for there. Homeliness was also an implicit contrast to the idea of living in an institution: that you should have the right, in a residential home, to choose what your home is like, rather than having to follow a depersonalising, standardised set of rules laid down by authority figures.

We made observations about the premises we visited from the point of view of how much control people had over them, and how they facilitated people's control over their own lives. As far as possible, we tried to do this from the perspective of the people who lived in the homes and what they wanted them to be like. Wherever people had the capacity to, we would start the visit with a tour from one of the residents, and would ask them questions on their views about different parts of the building as we went around.

We identified three main themes about premises in our research that were important to people living in the home: the extent of personalisation of the premises; the content, organisation and accessibility of information displays; and how people moved around and participated in the upkeep of the premises. Each of these themes is discussed below.

Personalisation of premises

On our Enter and View visits we witnessed a varying amount of personalisation in different homes. In almost all of the homes that we visited, we saw a good degree of personalisation in people's bedrooms. People had generally made their spaces their own, decorating the walls with posters, artworks by themselves and others, and photographs of their friends and families. Bedrooms also usually showed some evidence of the person's hobbies and interests, and suggested something about the extent to which they were able to pursue these in their everyday lives.

People were keen to show us their bedrooms, and would proudly explain to us what the different objects represented to them. People's bedrooms seemed to represent the spaces that were most homely to them, and where they were able to have the most control and to express themselves most effectively. One person spoke to us, for example, about their interest in playing an instrument, and about their favourite musicians, whose posters were on the wall; another shared their interest in good coffee, and talked to us about their coffee machines; another showed us their art supplies and some of the artworks they had made. People would also often display their achievements in their bedrooms, with a lot of certificates from different courses they had successfully completed.

Some homes demonstrated a greater degree of personalisation of bedrooms than others, however. Seven of the homes that we visited offered people the chance to have their room redecorated according to their preferences, but for others personalisation was limited to what people chose to put in their rooms. This could sometimes be for reasons of the capacity of people to choose or express how they wanted their room decorated, but some homes were able, by trial and error, to find, for example, a colour that someone was happy with, even though they were unable to express this directly.

Some homes showed a commitment to prioritising people's choice of decoration over cost and convenience for the home. One home, for example, who had redecorated a room prior to a new resident's arrival, found that this person and their family did not like how it had been done. The home quickly redecorated the room to their preferences, including a wall display about the various relatives around the world that this person was missing. Someone living in another home wanted to move from a ground floor bedroom to a first-floor bedroom because they liked the view, but had difficulty with stairs. The home therefore made renovations to allow this person to safely navigate the stairs and so move into the bedroom of their choice. These sorts of enabling adjustments allow people to access the right to choose their bedroom, without letting their disability be a barrier to that choice.

In six of the homes that we visited, there was a choice between living in the main house and living in a separate building with semi-independent flats. These usually had a living/dining area, a small bathroom, and a sleeping area. People who had chosen to live in these parts of a service particularly valued being able to choose this living arrangement. For some people this was because they found the main house of a service too busy or noisy, and being in their own flat made them feel happier and calmer and so helped them to manage their behaviour better. It was also important for people who wanted to improve their independent living skills, with a view to moving out into supported living.

Most homes also made efforts to allow the personalisation of communal spaces, though again, the extent to which this was allowed varied from place to place. Most homes did this through putting photos of residents on the wall, and sometimes these were in organised displays that were kept updated. In most homes people undertook some kind of creative activities, and often there would be artworks by residents on the wall. While this did give people significant input into how the home looked and felt, most of the decoration was often decided on by staff, with the personalisation being added on top of the decoration and interspersed with items chosen by staff. This was the case in 12 of the homes that we visited. In five others, signs of personalisation were minimal, with only a few photos here and there.

Five of the homes that we visited, however, offered something more substantial, and the personality of residents came through more prominently. In these homes this was usually because they had been consulted as to how the communal spaces were painted, and helped to choose furniture. In one home, for example, people had been invited to re-design the communal bathrooms, and had decided that they wanted a spa-style one, a sparkly one, and a more sober, formal one. In another setting, people preferred a setting with minimal stimulation, and had spaces with nothing hanging on the wall, but with decorative stencils and sensory materials on the wall, and simple furniture.

Information displays: content and accessibility

Most homes that we visited had information displays on the wall. There were some displays that were in every home, typically with some information about CQC registration, health and safety information, and information on how to complain. Many homes went further than that, and displays could be used in a way that empowered the people living in the house to know what to expect in their home, how to navigate it more independently, and how to develop their skills.

It is worth noting that managers of different homes had different visions for how the home ought to be, and this affected how they used displays. In some homes, they told us that they were trying to create a ‘homely’ atmosphere and thought that too many displays would make things seem too institutional, and too much like a care home. Eight relatives talked to us about the importance of homes being like an “ordinary family home”, and people living in services that had this aesthetic told us that they liked it. So, this does seem like a legitimate choice as one way of providing a home that people feel comfortable in.

However, it does seem that information displays can be used to positive effect, and that where they are used, it is important that they should be produced in a format that is accessible to residents. Seven of the homes that we visited had information displays that were either not in an accessible format, or were poorly organised and cluttered, making it difficult for people to understand them. In 14 of the homes that we visited, information displays were produced in an accessible format, and covered the main official topics around complaints and the registration of the service. Many of these homes also displayed activities timetables for the week, and the week's menu, though these were not always produced in accessible formats. These are helpful for people, who can see what they can expect to do each day, and for how long, and what they can expect to eat. They also were often physical evidence of collective decisions that had been reached in residents' meetings, and of the fact that they were going to be honoured.

However, one home had a more ambitious attitude to displays. One of these was the 'Many Pieces of Me' display mentioned in the section on staff above. This gave residents and staff information about the lives and personalities of the people living and working in the home. There were also chores rotas displayed in the kitchen, and accessible information about personal care skills. For example, there were displays about how to look after your mental health, and how to keep fit. These provided information that people could use to develop their independence skills, and that could be referred to by staff as they encouraged people to develop their skills. They therefore provided important aids in helping people to become more independent and to make their own choices.

Moving around and participating in the premises

While it was positive to see that people were being consulted about how their homes were set up and decorated, their involvement in home life could be augmented further by helping them to participate in the upkeep of their homes. When people were showing us their rooms, they were often particularly proud to tell us that they had cleaned or tidied it themselves, or to show us a neatly folded pile of laundry that they had washed themselves. This was also an opportunity to help people to maximise their capabilities.

The homes that had the most organised approach to this, had chore rotas posted on the wall, and residents were keen to point these out to us as they showed us around the home. In one service, all the cleaning tasks (except those requiring dangerous chemicals) were divided up between the residents. Laundry, tidying bedrooms, gardening, mowing the lawn (which had been risk assessed), cooking, washing up, cleaning and hoovering were all done by residents. There was a rota on display for people to sign when they had done their task. There was even a task given to one resident to check whether people have signed off their tasks, so that the rota itself was mostly managed by the residents.

While not everyone in the homes we visited would have the capacity to get involved in housework to this extent, where people are capable of it, this seemed to provide a well-organised and rigorous way to help people to take control of their own home. It also guards against the risk of institutionalisation that there seemed to be in one home, where someone told us that “everything is done for us”, and in which the idea of involvement in running the home seemed to be an alien concept.

Taking ownership of one’s home also seemed to be about how freely people moved around their home. In some homes that we visited, there were rooms which were off-limits to residents, and staff usually gave us a safety justification for this, for example that it was not safe for some people to enter the kitchen or laundry room. Deprivation of Liberty Safeguards needed to be in place before such a restriction could be imposed. These cases aside, people should be able to circulate freely around the communal areas of their home.

However, we observed that there was a difference between being allowed to do this in principle, and there being a culture in the home in which people actually did move freely through the home as they wished. For example, in most homes, people were allowed to enter the administration office whenever they wished, but it was a smaller number of homes where we witnessed people going in and, for example, taking things out of a draw, or fetching a photo from a wall, to show us. Similarly, while many homes gave people the option to be involved to some extent in making decisions about communal spaces, there were fewer homes in which we observed residents making suggestions to staff about repairs or new equipment, in a manner that suggested that they were used to seeing a response to their suggestions.

There were variations in how different people wanted to move around the home, and these preferences could be quite individual. For example, some people, who became overwhelmed by too much noise and social contact, still wanted to feel involved in the life of the home. It was important for these people to have spaces available in the home where they could find a balance that suited them. For example, one person we met took their lunches in a room that adjoined the main dining area, so that they could feel involved in mealtimes, without being too close, and so did not have to choose between eating in their room by themselves, or facing the noise and stimulation of the main eating space. One relative described a similar situation like this: “It's a marvellous sense of, there's this young man sitting at his desk or dancing around in his sitting room, and the door to his flat is permanently open. So, the stairs go straight down to the very small lobby, so he's part of the community but it's just that he's up these stairs.”

A selection of the homes we visited. Clockwise from top left: Joseph House, Reedham; St. Brannocks, Mundesley; The Old Rectory, Hevingham; Callum House, Norwich; Mandalay, Marham; Phoenix House, Snettisham; Whitehaven, Sheringham.

Premises, voice and control

Elements of an empowering approach to
the physical aspects of residential homes

BEDROOMS

Helping people to personalise their bedrooms with pictures and objects

COMMUNAL SPACES

Posting meaningful photos and residents' artwork on the walls

DECORATION

Going beyond pictures on the wall, letting people shape the whole look and feel of a home

INFO DISPLAYS

Accessible, well-organised displays which are enabling for residents

CULTURE

Encouraging a sense of ownership, participation and control in the home

Activities

The choice of daily activities is of course key to people's ability to be able to shape their lives and to find stimulation and fulfilment. When service users and their relatives were telling us what they liked about their residential care, activities were often the first thing that they mentioned. Similarly, when people talked about care that they had been unhappy with, a lack of activities was one of the most prominent complaints. One parent told us about a home they visited when looking for a placement for their son:

> "And all these residents sat outside because it was summer, and they weren't doing anything … And I thought, 'What do they do in the winter?' This is horrendous, and they didn't seem to have any daytime provision." In contrast, when they visited the home they eventually chose, they found that people, who had been out volunteering, "had been doing something meaningful. They seemed to have their own life … They seemed to be doing something, which they clearly enjoyed. And it was just so different from just sort of sitting around."

Another person asked their relative's social worker to get them moved from a home where their relative was rarely going out. However, when a new manager was recruited, who made sure that people were able to get out regularly, they reversed the request, and said that they never wanted their relative to move.

In this section, we will give an overview of the main trends we observed in the homes we visited, and give some examples of the approaches that residents were most happy with, and that maximised their choice and control over their lives.

Most of the people in most of the homes that we visited, and most relatives that we spoke to, told us that they were happy with the choice of activities that they were being offered. In almost every home that we visited, people were offered quite regular outings, and a range of activities inside their home, and they were regularly consulted about anything new that they would like to do.

Homes which were in rural areas on average offered fewer choices of outing. 11 of the homes that we visited were in rural areas, and some of them compensated for their remote location by investing in more amenities on-site, which expanded the number of in-house activities people could choose from.

For example, some homes had activity sheds in their grounds and dedicated activities staff (two homes), a sensory pool (two homes), a sensory room (two homes) and their own farm animals (three homes). Others hired in visits from external activities providers, including visits by animals (three homes), musicians (two homes) and art and craft teachers (two homes). Those rural homes which had access to several different vehicles did manage to offer more outings, although some homes had trouble finding enough drivers to fully make use of their transport.

Some homes offered more individual choice than others. Some offered predominantly communal outings because their residents had relatively fewer one to one support hours (because they had been assessed as having lower support needs). This could mean that they went out most often with several other residents and one or more members of staff. These outings were most often discussed and decided on at residents' meetings. This could end up diluting the amount of influence individuals had on what activities they undertook, especially in larger homes, where communal activities could struggle to meet the wider range of interests held by a larger number of people.

An important aspect of fulfilling activities seemed to be the need to help people to try new things and to broaden their horizons. Gentle encouragement by staff was important in helping people to take up an enriching variety of activities, since some people might be reluctant at first. Many people told us that pandemic restrictions had made this more difficult for many. As one relative told us, "during the pandemic, people had to learn to be inactive, and now they are having to learn to be active again, and it is taking time". This meant, for example, that some people who had formerly enjoyed swimming, but had trouble adjusting to new sensory experiences, needed to be assisted to gradually desensitise themselves to the sensations of being in water again. For others, they had not taken up the outings they had formerly participated in before the pandemic again, choosing to make a new start after restrictions were lifted. This was sometimes related to what relatives told us was an age-related 'slowing down' and wanting to take up less physically demanding activities.

Day Services

Some people found more variety in their activities by visiting day services during the week. Both residents and relatives who we spoke to were happy to visit these services, which were often able to provide a wider range of activities than most homes could provide in-house. These might include crafting sessions, life skills training, games, music sessions, sports, fitness, cooking, gardening, and walks. Some providers who operated several homes in the same area, also ran a day service as part of their business. Some people referred to their activities at Day Centres as 'work', especially in cases where they were contributing to something that provided a service or product for the public. Some day centres, for example, had farm activities or a café for people would work in, and people seemed to find these kinds of activities particularly meaningful.

The social aspect of visiting a day centre was also mentioned as an important feature that people valued. Care home residents often have only limited control over who they lived with, but at a day centre, where there were more people around, they could choose who to spend time with. For some people, these were their only opportunities to make friends outside their home and their families, and when they had been attending day centre for many years, these friendships were vital to their wellbeing. Two people we spoke to were adversely affected by the threatened withdrawal of their day service. One person, who had been attending their day service for several decades, reached the age limit of 65 years old, when they were supposed to stop attending. On that occasion, the home worked productively with social services and the day service to ensure that person's continued attendance. Another person, who was blind, had been attending a day service for many decades, and was unable to participate in many activities, but enjoyed the social aspect and the relationships she had built up over many years. When the service was re-started after the pandemic lockdown, her funding was not reinstated for this, and she experienced this as an important loss of social connections.

Three relatives spoke to us about what they saw as restrictive criteria around which day services their relatives could access. One person told us that their relative had formerly been able to attend a day service in another part of the county to his residential home, but that at a certain point rules had been changed so that they had to choose a day centre closer to home, but which he was less happy with. Two other people had taken their relative out of a day centre which they had not found stimulating, and had arranged for their relatives to go to do activities on a farm, an activity which NCC had declined to fund. As a result, relatives were having to pay their own money to send their relatives there. This could suggest that people who do not have relatives who are willing to do this, could be missing out on more stimulating day services to visit.

Figure 4: An artwork by someone we interviewed in one of the homes.

Best practice and personalisation

The people we spoke to who said they were most happy and fulfilled in their activities were those who were supported to develop their own personal interests in a flexible and responsive way. Given the different levels of independent skills and support needs that people had, how this was achieved varied. Those with higher support needs achieved this through attentive, creative and flexible support from their keyworkers. People with lower support needs achieved this through support and encouragement to develop their independent living skills, and to try new things until they found activities that they wanted to invest more time in.

“The process has been joyful”.

One service that was delivering particularly responsive support to people who had substantial one-to-one hours each week, demonstrated this responsiveness both on a day-to-day basis and over the long term. One person, for example, told us about how they had gone on an outing with their keyworker the day before, where they had collected blackberries and other natural objects. Given this person’s love of art, their keyworker had supported them to use blackberry juice and a feather they had found to make a painting using the materials they had found. Alongside this creative day-to-day approach, a relative told us that staff would constantly be looking out for new activities for people to try, and trying to strike a balance between offering people activities that they already liked, but also be trying to expand their activities into new areas. This relative told us that “the process has been joyful”, and this view was supported by what residents told us when we visited this service. People living in this home were able to invest in building up their skills in areas they were interested in, while also making new discoveries.

In another service, where people had lower support needs, a different approach was taken. Given that people here had little one-to-one time with staff, outings away from the local area were usually undertaken in groups. These were decided on communally and residents said that they enjoyed these. At the same time, people had been supported to develop their independence, and to find outside activities that they found fulfilling and wanted to invest their time in. This involved helping people to develop the skills and confidence to use public transport, and to handle tickets and money. This meant that people here were able to develop creative pursuits, and this could have transformative effects for them. One person talked to us with great pride about his music lessons and performances, and his relative described them as marking “quite a turning point in his life” that gave him greater confidence and happiness.

The relatives that we spoke to with family members at this service, attributed much of this success to the efforts of the home’s manager. They spoke of his willingness to encourage people to try new things, coupled with having a certain shrewdness about what different people were likely to enjoy, and a determination to make activities possible by creatively overcoming financial and administrative barriers.

Best practice according to service users and their families

What mattered most to people about their activities:

- People with high support needs valued attentive activities support, which combined day-to-day individualised responsiveness and the chance to develop their interests.
- Some people needed encouragement to try new things, and were grateful for this despite their initial reluctance.
- People with lower support needs appreciated support with developing the independence and confidence to be able to go out and participate in activities by themselves.
- Most people were happy with their day services, and many particularly liked work or work-like activities that they undertook there.
- People also emphasised the social value of day services in terms of having a wider choice of friends and relationships built up over many years.

Friendships and relationships

Closely related to the activities people undertake, are the friendships and relationships that people can develop. Research suggests that people with learning disabilities have fewer friendships than non-disabled people, and that their relationships tend to be with a narrower range of people (Harrison et al., 2021). Friendships and loving relationships are, of course, vital for the wellbeing of people with learning disabilities, as they are for any other group (Mencap, 2016), but people with learning disabilities often need support to help them form and maintain relationships. We therefore asked people living in residential homes and their relatives about their friendships, and about the support that they received to form and maintain relationships (relationships with care staff are also often central to people's lives in residential homes, and we discuss these in the section on staff, above).

We found that in three of the homes we visited, people had relationships with their family members and staff, but not with each other. The reason given by staff and family members in these settings was that people chose not to associate with their co-residents, for reasons related to their condition. In four homes we visited, people told us that they had meaningful relationships with co-residents, as well as care staff and their families. In 13 of the services we visited, people had meaningful relationships with co-residents, staff and families, but also had some kind of social activity outside the home, in the form of either a day service for people with learning disabilities or autism, or a social club for people with disabilities. Of these 13 homes, in three of them, people also had relationships with friends outside the home, independent of day services or social clubs. We only came across one person in our visits who was involved in a romantic relationship. Finally, in one home, residents did not have any surviving family members, and their main relationship was with staff.

Most of the people that we spoke to in the homes, told us that staff help them to spend time with their friends. In the Opening Doors focus groups, people were less positive about this, with 15 people (out of 22) saying that staff did help them, but 5 saying that they did not (two people did not answer this question). People were also asked where they have friends, and people answered as follows:

Setting/group	Co-residents	Staff	Day centre	Social club	Community life	Other places

Number	11	10	10	9	5	5

They were also asked where they did not have friends, and answered as follows:

Setting/group	Co-residents	Staff	Day centre	Social club	Community life	Other places
Number	3	4	7	7	7	6

This data suggests that participation in day services and social clubs are very important to people's social lives. These are, for many, the only places where they can expand their social networks beyond the people in their home, and where they have a wider selection of people from which to choose who to spend time with. We were struck on our visits by how few people living in residential homes had been able to maintain relationships with friends that they knew before they moved into their home, or who they knew independent of the home and day services and clubs. As mentioned in the section on shortages of suitable care placements, people's reluctance to take up otherwise suitable placements was often based on fear of losing touch with friends if they would have to move away from their local area. This finding suggests that people need more support to maintain their old relationships when they take up a new placement.

Despite their positive role, the nature of these services is that people are offered the opportunity to socialise with other people with learning disabilities and autism, but not with people without these conditions. In addition, while many care home residents spent time out 'in the community', this rarely seemed to include forming relationships with non-disabled people. Two service users we spoke to had formerly used the 'gig buddies' scheme run by Mencap in Norfolk where people with learning disabilities were paired up with volunteers who shared their taste in music, to go to gigs together. They were both sad that it had been discontinued, and said that it had been an important social outlet for them. More thought could be given in the sector in Norfolk to re-starting this, or similar schemes, to broaden the social horizons of people living in residential care.

Finally, the fact that we met almost no-one in a romantic relationship in residential care suggests that much more support is needed for people to develop and maintain romantic partnerships. As our previous review of residential care for people with learning disabilities and autistic people found in 2014, (https://healthwatchnorfolk.co.uk/wp-content/uploads/2023/07/Enter-and-View-residential-settings-for-adults-with-LD-and-autism-March-2014.pdf), effective support in this area still seems to be lacking.

KEY FINDINGS ON RELATIONSHIPS

Most people happy with staff support for friendships

More support needed to maintain old friendships

More support needed for friendships with non-disabled people

More support needed for romantic relationships

Homes' interactions with residents' families

Almost all the family members and service users we spoke to said that home staff were good at facilitating contacts with families. For most family members who we spoke to, this meant being able to visit the home on a regular basis, and people were able to do this, reporting that homes put no restrictions on their visits. Some people told us that they particularly appreciated social events being held at the home, as it gave them the chance to get to know other relatives and residents better. These visits had often been stopped during the pandemic, and in many cases were yet to restart.

Some relatives mentioned to us that, as they got older, they were no longer able to visit their relatives as often as they would like. Two homes provided transport to take people to their family home either for a day trip or for overnight stays, and relatives at these homes told us that this was a vital service for them. Given that many parents of people in care are elderly, this might be a service that more homes could consider offering. Another home, whose residents' families all lived outside Norfolk, had a building next to the main home for relatives to stay in. This allowed relatives to stay there for a few days at a time, close to their family member, in a space where the home resident could spend time with them in a setting that was familiar to them. Again, this was praised by relatives from this home, and could be adopted elsewhere, where a provider has sufficient resources.

Relatives were also mostly happy with how homes communicated with them. Some homes had arrangements for regular updates, either by phone or email. However, most people told us that homes would keep them updated with phone calls whenever there was a problem, and would also discuss how their family member was doing during visits to the home. Three people told us that their communications with the home were hampered by poor internal communication amongst staff, for example when one shift had not communicated to the next shift what a relative had requested, and so had to be asked again.

Two main areas of concern were reported to us on this topic. One was that some relatives found that their family member would not receive a standard of care that they were satisfied with, unless they actively lobbied the home on an ongoing basis. Rather than finding that homes responded to their feedback and sustainably changed their practices, they found that they had to keep checking that changes were maintained. 8 out of 58 relatives (14 per cent) raised this problem with us, and several of them wondered aloud what would happen to their relative if there was no-one to lobby on their behalf. This is a particular worry for ageing parents who worry what will happen to their adult children when they are no longer alive.

For some of these relatives, this put significant strain on them. As one person told us,

> "I feel I'm constantly running to keep up, checking what was happening, which is not-- it's not comfortable for staff because I'm continually questioning. But I've learned if I don't, sometimes things don't happen. It's like having a job. My husband goes ballistic. I spend more time, in some ways, than when [our son] lived with us because I feel I'm the only person that is keeping an overview."

The other area of concern was relatives who reported to us their worries about being labelled 'problem parents' or 'interfering parents' (as also mentioned in the section on Managers). Five people spoke to us of their fear of complaining to homes, because of what might happen to their relative. One of these fears was the worry that if complaining led to a breakdown in their relative's placement, then they could end up being sectioned and sent to a secure unit. These people were particularly worried, given the abuses that have been uncovered in some secure units, but also the prospect of their relative being sent to an out of county placement, and their condition deteriorating further as a result.

There was also a perception amongst these respondents that, if they became labelled as a problem relative, then this could lead to them not being listened to by both home staff and social services. One person spoke to us of how they tried to pre-empt this sort of reaction through how they spoke to home staff:

> "[My husband] and I made a decision, this is how we were going to be with carers and managers. We weren't going to do chatty and informal. We were going to be formal. Not being snooty, but what we decided is that if you behave like professionals yourself and not needy, grieving parents ... then they develop quite a professional relationship with you."

Key findings on homes’ interactions with families

Most people were happy with homes communications with them, and how they supported relatives to visit homes. However,

- More support could be given to help people visit their elderly parents at home, as they become less able to travel.
- A significant minority of relatives reported being under considerable strain, because they kept having to check that homes were maintaining appropriate levels of care for their family member.
- Some of these relatives were worried about the adverse consequences for their family member, and for their continued access to their family member, if they kept complaining. More reassurance and safeguards may be needed to ensure that relatives can express themselves freely without negative consequences.

Feedback from secure in-patient units

Introduction

We carried out Enter and View visits to four of Norfolk's secure inpatient units for people with learning disabilities and autistic people. There are two main types of inpatient units for people with learning disabilities and autistic people: Assessment and Treatment Units (ATUs) and forensic units, of which, in Norfolk, there are medium-secure, low-secure and rehabilitation units (there are currently no high-secure units in the county). There are five secure in-patient units in total in Norfolk, with two being run by Hertfordshire Partnership University NHS Foundation Trust, and three being run by the Priory Group. We visited a unit from each of the above categories: an ATU and medium secure unit run by the Hertfordshire Partnership, and a low secure and rehabilitation unit run by the Priory Group.

Our data collection for these settings involved 2-3 hour visits to each service. We invited family members from all the units to give us their feedback, but relatives from only one of these units got back to us. We therefore supplemented our visit data with some feedback from a user-led advocacy group (Opening Doors) that regularly visited two of these units, who also carried out a focus group in one of these units.

In this section we will discuss the listening mechanisms that were in place in the units to try to capture patients' voices and make sure that they were responded to, patient feedback on their quality of life in the units, their relations with staff, and finally the most significant problems that were reported to us from these units.

Listening and responsiveness to patients

The range of meetings and consultation mechanisms in the secure units were more formalised and wide-ranging than those that we observed in the care homes. This is partly related to the legal checks and balances that are in place to try to ensure that people's rights are being respected whilst they are being deprived of their liberty. It also seemed to be related to a commitment by staff and managers to an open and consultative culture, which we discuss below.

People with learning disabilities who are detained either under the Mental Health Act must have regular Care Programme Approach (CPA) review meetings and Care and Treatment Review (CTR) meetings. Both meetings should provide opportunities for patients and their families to give their views on the treatment that they are receiving (NHS England, 2018).

CPA reviews last for around an hour and happen every six months. They involve the patient, their care co-ordinator (usually a social worker, psychiatric nurse, or occupational therapist), and the multi-disciplinary team that is caring for the patient, which may typically involve psychologists and psychiatrists, learning disability nurses, speech and language therapists, occupational therapists, social workers and others. These ought to give patients the opportunity to talk about the care that they think they should get, and about the progress they think they are making.

CTRs happen once a year and are chaired by the commissioner who has placed the person in in-patient care. They are a review that is more independent of the team caring for the patient, and include an expert by experience who has lived experience of services, and an independent clinical expert. The review will last around a day, to allow time to be spent with the patient and their carers and family, to try to understand their views.

In addition to these meetings, in all three of the forensic settings, staff told us that regular patient meetings were held. These had slightly different formats in each place. The rehabilitation unit we visited (which housed nine patients) had fortnightly group meetings to discuss patients' feedback about the service and anything they would like to see changed. The low-secure setting (which had 16 patients) held monthly patients' council meetings for people to raise any concerns that they had, and to discuss what activities and facilities they would like. Patients also elected representatives to participate in various meetings which oversaw important aspects of life in the hospital, such as the reducing restrictive interventions meeting and physical health meetings.

The medium-secure setting, similarly, had monthly patients' voice meetings, with an agenda established by patients themselves, and decisions being fed into the governance of the hospital. In addition, patient representatives sat on the security committee, where they had the opportunity to challenge any security restrictions they thought were unjustified, and hospital leaders had to provide a reasoned response. If they were unable to, then the restrictions would need to be relaxed, and staff gave us two examples of when this had happened. Patient representatives also sat on the activities planning committee.

The ATU that we visited also held regular patients' meetings, and the minutes of these were produced in Easy Read format and posted on a noticeboard in the unit. In both settings run by Hertfordshire NHS Partnership, there were monthly patient satisfaction surveys that patients were involved in, which resulted in 'You said… We did…' responses, showing how feedback had been responded to. These were also posted in Easy Read format on noticeboards. In the ATU there were also a range of different one-to-one meetings to consult patients. Once a fortnight, each person's multi-disciplinary team would meet to discuss their care, and the patient would be present for the first part of this meeting, to let staff know how their week had been. Each person also had a fortnightly personal and social development meeting to discuss their learning needs and desires, and would complete an Easy Read activity quiz which would be used to produce their weekly activity plan.

It is worth noting that we did not witness these committees and meetings in action during our visits, and so cannot be certain of how they operate in practice. However, their existence does seem to suggest that there are ongoing, organised attempts to take patient voice seriously in these settings.

These settings also brought in external assistance in helping them to engage better with patients. The two settings run by the Hertfordshire partnership had weekly visits from Opening Doors, where patients would receive advice and training in how they could better advocate for themselves. Managers of all four settings told us that patients could be appointed an independent advocate if they requested one, and contact details to complain to the CQC were prominently displayed in accessible formats in all the settings (alongside details on the internal complaints process).

Engaging with and listening to families

All the secure units that we visited held regular family carer days, with the rehabilitation unit holding these once a year, and the other units holding them more frequently. These give opportunities for family members to visit other carers with relatives in the unit, chat with staff about the running of the clinic, and to meet their own relatives and other patients. Opportunities are also given to discuss individual patients' issues with staff members in private at the end of the event. The low- and medium-secure units also had resident social workers who provided a point of contact between the units and families.

The family members who we spoke to from the low secure unit were very positive about these meetings. As one relative put it, "Even the higher ups have been there when they've had carers days, we've been made welcome. We've had a barbecue, they've all come over and spoken to us. So, it's been an inclusive relationship all round." As another family member from this unit told us, these carers' days were initiated at the suggestion of two patients at the low secure unit, who had previously lived in the medium secure unit where these days were a regular occurrence, and they saw this as an important instance of responsiveness on the part of the unit.

These relatives also told us that they were happy with the way that the unit communicates with them, with all three relatives telling us that staff were easy to contact, and listened to their feedback and made changes in response. One person told us that staff responded to feedback about how to understand and respond to her relative's behaviour, and as a result his treatment had progressed more quickly than it had in previous secure units where he had lived, where they had not responded to similar feedback. However, one person gave more mixed feedback, telling us that whilst they could contact the ward whenever they wanted to, they would like the unit to take the initiative to give them updates about their family member.

Taking relatives’ knowledge seriously

Relative: I'll give you an example. A carer was getting hurt. He went in to help the carer ‘cause he doesn't like to see people getting hurt. He got in the way, and he got put in seclusion for it. And I explained to [the resident social worker] why he done that. It was self-preservation. He doesn't like to see anybody getting hurt. And she listened and it was like, wow, they're listening. You know? So, I was well happy right from the beginning.

Interviewer: Was that something new, for you to be listened to?

Relative: Oh yeah. I mean the carers at [his former unit] would listen but when they told the higher ups, they wouldn't action it. They wouldn't take notice of what I was saying. Like, don't chase him or don't watch him when he is eating. He doesn't like people looking at him when he is eating. Put him in a separate room or sitting right at the back of the room so he can see everybody, but they can't see him. They did that [in his current unit], they were spot on.

Feedback from patients

During our visits we spoke to 17 patients: five (out of seven) in the rehabilitation unit, six (out of 16) in the low secure unit and six (out of 20) in the medium secure unit. Four people also attended the focus group carried out by Opening Doors in the medium secure unit. None of the six patients in the ATU wanted to speak to us for any length of time, and only two of the people we met were able to express themselves verbally. However, we did observe patients interacting with staff there, and asked Opening Doors for their impressions of how person-centred the service was, given their weekly visits to the unit.

Gauging patients' satisfaction in secure units is more difficult than in residential homes, because, by definition, people living there have not chosen to be there. A significantly higher proportion of people in these units said that they would rather not be living there, and were keen to leave, compared to the residential settings. This is perhaps unsurprising, given that they had been deprived of their liberty. Most patients did report to us, however, that, under the circumstances, they were satisfied with their lives in the units. In the rehabilitation unit everyone we spoke to said that they were satisfied, and in the medium secure unit, four people told us that they were satisfied, against two who said they were not satisfied. In the focus group carried out there, when selecting from three options, one person said that they were 'fed up' living there, two said that things 'could be better', and one person said that they were 'happy'. In the low secure unit, most people we spoke to avoided answering the question directly, though two people told us that they were unhappy.

There was mixed feedback about staff, but it was positive on balance. Relationships between staff and patients did not seem to have the same levels of affection that relationships in residential units did, even when they were positive. The data from the focus group in the medium secure unit supports this, with all respondents specifically saying that staff were not their friends, whereas only four out of 22 people from residential homes said in focus groups that staff were not their friends. A staff member in the low secure unit told us that, although some patients were friendly with them, many patients viewed staff as people who could help them to "get what they wanted", but would not want to engage with them much beyond that.

There was some variation across the different settings in levels of satisfaction with staff that patients reported to us: all five of the people we spoke to in the rehabilitation unit said they were happy. In the low secure unit people seemed reluctant to respond directly to the question for the most part, and in the medium secure unit, four out of six people told us that they were happy with staff, against two who were unhappy. In the focus group in this unit, two of the four participants listed staff as one of their two 'Top things I like' about the service, and one person listed 'staff's attitude' as one of the 'Top two things I do not like'.

Our observations of staff interactions with patients suggested a culture of openness to criticism from patients. For example, on a few occasions, when we spoke to patients in a good mood who gave positive feedback on all aspects of the unit, staff overhearing would tell us that this particular person was not usually so positive, and encourage them to tell us what they might say about the unit when they were having a bad day. The interactions we observed between staff and patients in the forensic secure units were respectful, and often playful, with patients making fun of staff and receiving a cordial response. In all three of these units, patients told us that they knew how to complain, that people made use of complaints procedures quite often, and most people said that complaints were responded to, to their satisfaction, though two people we spoke to disagreed.

In the ATU we visited, relations between staff and patients appeared to be closer, seemingly because people there needed more intensive support to cope with their mental health conditions. We observed staff successfully calming a very distressed patient down in a compassionate way that demonstrated good knowledge of the patient's preferences and history. Staff also demonstrated how they were adjusting various aspects of this person's life and the organisation of the premises to make them happier. When we sought feedback from a staff member at Opening Doors from their regular advocacy training visits to this service, we were told that staff are caring and work well with the patients, and that the culture of the unit is open to scrutiny and advice from outside organisations. We were also told that there is a person-centred culture in the unit, working hard to allow patients to express themselves openly, and to follow their interests and preferences as far as possible.

Discharge delays

The main barrier to patient voice and choice in the in-patient units were delays to being discharged. Many patients were very keen to leave these units, and often were unable to do so even though they were ready to, due to shortages of suitable social care placements in the community.

In the ATU we visited, the manager told us that the unit had gradually changed in nature since its establishment 20 years ago. ATUs are intended to provide temporary placements for people whose residential care placements are in danger of breaking down because those placements are struggling to manage someone's mental health. This is intended to range from around a six week stay, to around a six month stay, depending on the treatment needs of the patient. While this unit has historically had a successful record of moving people back into their community placements, people with more complex mental health problems have gradually accumulated in the unit, and now occupy most of the available beds. One of the patients has been on the unit for four years. We were told that these longer stays are due to the difficulty of finding suitable placements for these patients in the community, because of their more complex and specialised support needs. This has meant that the unit has had to adapt to providing long-term rehabilitation treatment to their patients, rather than the shorter-term treatments it was originally intended for.

These patients often need to have bespoke community placements set up just for them, sometimes in a dedicated building, and usually with specialist staff hired specifically for that person. This means, due to the scarcity of suitable buildings and the current national shortage of qualified staff, that setting up these placements is very time consuming. Most of the patients in this unit were very keen to move to a community placement, and staff told us that their frustration was one of the factors making their behaviour more difficult to handle. The unit has identified suitable placements for most of its patients, however, and has set a timetable for most of them to leave in 2023. Some of these properties are being built under NCC's building programme, discussed in the section on professionals' views of the sector, above.

In the three forensic units we visited, we were told about a similar set of obstacles, although the blockages seemed not to be quite so severe. In the low secure unit we visited, the hospital manager told us that four people had been discharged in the previous few months. The managers we spoke to gave us three main reasons for delayed discharges. Firstly, they told us that part of the variation in length of stay in these units was due to the variety of conditions that patients have, some of which take a long time to treat successfully. Secondly, it could be time-consuming to go through the necessary legal processes of having Ministry of Justice restrictions removed, and getting appropriate Deprivation of Liberty Safeguards (DOLS) in place before the person was discharged. They mentioned significant delays in getting DOLS signed off by the Court of Protection, and without these it was much more difficult to persuade a community provider and a local authority to take a person on. These delays are a national problem: in 2021-22, only 20 per cent of standard DOLS applications in the UK were completed within the statutory timeframe of 21 days, with applications taking an average of 153 days to complete (Fouzder 2023).

Thirdly, the senior staff in these units had the impression that, given the shortage of social care placements, services could ‘pick and choose’ between different prospective residents, and would tend to avoid people with a forensic history. The units with patients from outside Norfolk would try to discharge people back into their home local authority area. One manager suggested that some local authorities were reluctant to accept people back onto their caseload, if they had a complex or difficult history.

While we cannot independently verify these explanations, they do chime with experiences in other parts of the country (Ince *et al.*, 2022, pp. 8–9), and are a huge source of frustration for the patients that we met.

Key findings on secure in-patient units

- Many patients did not want to be living in secure units, but most felt that staff did a good job, and that they were treated fairly.
- All the units seemed to have thorough mechanisms for gathering feedback and allowing patients to participate in the governance of the units.
- Our observations suggested that the units had cultures which were open to external scrutiny, and they actively elicited negative feedback from patients.
- Carers’ days were a very popular innovation with patients’ carers and could be adopted by secure units in other parts of the country
- The blockages preventing timely discharge are worrying, and some patients are still facing unacceptably long delays to discharge.
- NCC’s new housing programme seems to be helping to clear some of this backlog, but it remains to be seen whether it will be sufficient to cope with all of current or future demand.

Feedback on the broader health and social care system in Norfolk

Beyond the views that we have gathered on life in residential homes and in-patient units, we also asked people to provide feedback on their engagement with other parts of the health and social care system in Norfolk. Family members spoke to us most about their and their relatives' experiences of social workers (and the annual review process for people's care packages) and GPs. These topics are discussed in turn below.

Relatives' interactions with social workers and the annual review process

Each person with learning disabilities and each autistic person who is receiving support from NCC to access residential care, should in principle have their care package reviewed annually by social services. People's needs can change over time, and they might have developed additional support needs, or conversely might have gained more independence skills and they might need less support. Relatives of the person in residential care are often involved in this process, as is the person receiving support. For many of the relatives we spoke to, this was an important opportunity for them to get information on their family member's care, and to request changes to their support. As noted in the section, 'Views from Professionals', a new review process by NCC's learning disabilities commissioning team has been ongoing since 2021, to review all people receiving care funding from NCC, on a provider-by-provider basis.

Most people that we spoke to were happy with the annual review process. Some people mentioned that they have had problems with review processes in the past, but were mostly happy with how it had been working more recently. Some people reported delays in annual reviews during the Covid pandemic, but six people whose relatives' care had been reviewed recently, reported that they were happy with the process, and thought that the outcomes were fair and met their relatives' needs. Three people had felt that in the past there had been pressure to move their relatives into a different service for reasons of cost. However, they told us that in their most recent reviews, there was a more sympathetic approach, and they were reassured that their family members would not have to move.

A minority of family members did report some difficulties in their interactions with social services. Five people reported that they found it difficult not having an allocated social worker for their relative, as many people had formerly. Most people now have a different social worker or assistant practitioner for each annual review, due to a shortage of qualified social workers. People told us that this meant that they would have to spend a long time explaining their family-member's often complex history anew each year, and also that it can take a long time to get to know someone with learning disabilities or autism, and the ways that they communicate. As one relative told us:

> “Invariably I would say to the social worker, ‘Have you ever met [my daughter]?’ ‘Uh, no.’ So how does a social worker do a review on a learning disabled adult if they've never, ever met them?”

Five home managers also told us that they found it more difficult to communicate with social services, given that they no longer had a named social worker for each person.

Four people who had tried to contact social services between reviews to raise issues, had found that it was difficult to get a response, and told us that they thought this was related to high staff turnover: they would speak to someone who promised them a reply, and when they called to enquire about the reply, they found that this person had left. They told us that they were frustrated that it was so difficult to talk to someone with the authority to make the changes they were requesting.

The relatives we spoke to recognised that this was due to a national shortage of social workers, and were keen to say that they did not blame individual social workers or NCC for these problems.

Annual health checks, general practitioners and dentists

People with learning disabilities are eligible to have an annual health check with their GP. This is because people with learning disabilities often have poorer health than the rest of the population, frequently because of health problems going undetected. During the Covid pandemic the rate of people in Norfolk undergoing their health check annually dropped, to 45 per cent (at the end of January 2022, according to Norfolk Health Overview and Scrutiny Committee minutes, March 2022). We were told that the health check rate had increased to 70 per cent as of June 2022, with ambitions to increase this further.

In all of the homes that we visited, managers told us that residents had all undertaken health checks in the preceding 12 months. Most managers also told us that the GPs people were registered with were responsive, and that care was provided with reasonable adjustments for people’s conditions. Three managers reported problems with the prescribing of medicines, where people were either not receiving their medicines on time, or were being prescribed the wrong medicine.

Most people we spoke to in homes about their doctors told us that they were happy with them, and feedback from relatives was similarly positive. In the Opening Doors focus groups, 14 people answered the question, ‘Do support staff help you to look after your health?’ 11 people responded that they were happy with staff’s help, two said it could be better, and one was unhappy. All 14 people agreed that they were able to see health professionals when they needed to. We received three pieces of negative feedback from relatives: One person told us that it had been difficult to arrange a GP appointment for their son; another told us that staff at the GP surgery were having trouble getting a blood sample from their relative; and a third reported that a GP was not respecting their power of attorney over health decisions regarding her relative.

Finally, we did occasionally hear negative feedback on dentistry. Three home managers reported difficulty in getting appointments for residents, and two relatives reported the same problem. Given the large number of reports of problems that Healthwatch Norfolk receives about the availability of dental care in Norfolk, this seemed to reflect a lower level of concern than there is in the broader population.

Key findings on wider health and social care services

- Most feedback on people's most recent annual reviews with social services was positive, despite some negative experiences in the past.
- A minority of family members were unhappy that they no longer had an allocated social worker for each annual review, and thought that this was particularly unsuitable for people with learning disabilities.
- Most feedback on people's treatment from GP surgeries was positive, with only a few isolated problems.

Conclusion

The feedback that we gathered during this project has yielded substantial positive feedback and useful examples of best practice. In our attempt to gain an overview of how people are being listened to in the sector, we have not found that the problems present at Cawston Park are widespread in the sector. In most cases people have avenues for having their voices heard, and most relatives felt that they were being listened to well.

However, the people we spoke to also identified several important areas for improvement, we which summarise below.

Recommendations for providers

Staff:

- The people we spoke to most valued reciprocal, non-hierarchical, family-like relationships with staff. This suggests that providers should find ways to encourage staff to develop relationships with residents based on shared interests, a balanced sharing of personal information, and the empowerment of residents. This means supporting, wherever possible, keyworker stability for residents, to allow for longer-term, deeper relationships.

Managers:

- Families particularly valued managers who were well-informed and engaged in the everyday life of the home and the people who live there. Managers should therefore ensure a regular presence in the everyday life of the home, and avoid delegating this to deputy managers or other senior staff.
- Clear and honest communication was particularly valued by families. Particularly when problems or disagreements arise, transparency, regular communication and an open-ness to compromise and accepting the suggestions of family members can avoid damaging conflicts.

Premises

- While most homes made some efforts towards personalisation, more could be done to consult people more fully about the decoration of both bedrooms and communal spaces, to allow people to influence the overall look and feel of the home.
- If it fits the ethos of homeliness that a home is seeking, more use could be made of well-organised and accessible information displays. Greater use of

these could be made to share more information about staff with residents, and to use as education and enablement guides.

- Providers should take care to ensure that people are participating in the upkeep of the home to the extent that they are capable, as this was not always the case in the homes that we visited. People who were participating in this way were particularly proud of it.
- Homes should seek to establish everyday habits that show people that they can move around homes at will and make suggestions about upkeep or changes at any time. While this is technically allowed in many of the homes we visited, this did not always seem to have filtered through to the expectations and habits of residents.

Activities

- Providers should take care to constantly encourage people to try new activities, rather than take a refusal at face value. The people who had broadened their horizons and tried new things generally reported being most happy.
- Where people have substantial one-to-one support, attentive support should be given to people's daily activities, using creativity to allow them to follow their interests both in the moment, and to invest in longer-term interests over time.
- Where people have more capacity for independence, homes should not rely on communal activities to keep them happy, but invest in developing their independence skills and confidence, so that they can follow their own interests with minimal staff support.

Friendships and relationships

- Relatively few people that we spoke to had managed to maintain friendships that they had established at the previous places they lived. This suggests that homes could do more to support people to keep in touch with old friends.
- Only one person we met was in a romantic relationship. This suggests that people living in homes are not given the support that they need to develop romantic relationships. Homes may need to invest in training in how to support these relationships, as this was an issue that did not seem to be on the agenda for most of the homes that we visited.
- Providers should seek more opportunities for residents to form friendships with non-disabled people outside the home, since meaningful community participation will not be achieved without this. Although this is partly a

problem of ableism in wider society, more thought could be given as to how to develop programmes similar to gig buddies, to provide more opportunities for barriers between disabled and non-disabled people to be broken down.

Homes' interactions with families

- More support could be given, as relatives age, to help people to visit their elderly relatives, when they are no longer able to visit their family member in the home.
- Homes should ensure that, especially when relatives have requested changes to someone's care, that these are followed up consistently, and that relatives are given regular updates as to progress on making the changes.
- Providers should also take steps to reassure relatives that, if they complain, that no adverse consequences will ensue, for their family members, or for their access to their family members.

Recommendations for the Health and Social Care system in Norfolk

As discussed in the section on 'Views from Professionals' above, many of the issues raised for the broader health and social care system in Norfolk are already being addressed, or there are plans to address them. These include the central problems of the availability of sufficient care for people with complex needs, and more enabling forms of accommodation for those who will benefit from that; and the central issue of the shortage of care workers and its knock-on effects for people in care homes and secure units. The latter is partly a national issue, as is the shortage of social workers which makes maintaining a regular social worker at annual reviews so difficult.

However, some issues did come up in people's feedback, that could be addressed:

- Norfolk needs to develop more specialist placements for people with learning disabilities and autistic people, in all areas of the county, particularly to provide places more promptly for young people when they become adults. Current efforts to develop these placements should therefore be continued and perhaps strengthened.
- As people age and their support requirements change, steps should be taken to ensure that they are able to remain active and stimulated if they need to move home.

- Some relatives were paying for some types of day service that NCC had declined to pay for, but which service users and their families found very beneficial. It might be worth investigating whether funding could be found for a broader set of day services might be funded. When considering funding decisions on day services, feedback suggests that people's social lives and long-standing relationships should also be considered, and not just participation in activities.
- Some thought could be given to the fear of some relatives of being labelled 'problem parents' or similar, and how these fears could be allayed, and safeguards put in place to make sure that these labels are not used inappropriately.
- Given that some people living in residential care value relationships with non-disabled people, some consideration could be given as to how to support homes to support people to form these relationships, or even to re-establish a gig buddies scheme, or similar, in Norfolk.
- Our findings suggest that people living in residential care are being denied the opportunity to form romantic relationships. More support could be given to homes to help them to build the capacity to support people to establish these relationships, where this is an aspiration.

References

Dale, C. and Ryan, T. (2011) ‘An ever watchful eye: the Care Quality Commission inspection regime failed to protect patients at Winterbourne View. Colin Dale and Tony Ryan suggest an alternative approach’, *Learning Disability Practice*, 14(8), pp. 9–10.

Department of Health (2012) ‘Transforming care: A national response to Winterbourne View Hospital’. Department of Health London.

Evans, N. (2022) ‘How much has care been transformed ten years on from the Winterbourne View scandal?’

Fouzder, M. (2023) Deprivation of liberty safeguards reform delayed. *Law Gazette*. Available at: https://www.lawgazette.co.uk/news/deprivation-of-liberty-safeguards-reform-delayed/5116409.article (Accessed: 25 July 2023).

Harrison, R.A. *et al.* (2021) ‘Social networks and people with intellectual disabilities: A systematic review’, *Journal of Applied Research in Intellectual Disabilities*, 34(4), pp. 973–992.

Ince, R. *et al.* (2022) ‘“Why are we stuck in hospital?” Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK’, *Health & Social Care in the Community*, 30(6), pp. e3477–e3492. Available at: https://doi.org/10.1111/hsc.13964.

Mencap (2016) *Friendships - research and statistics*, *Mencap*. Available at: https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/friendships-research-and-statistics (Accessed: 29 May 2023).

Mencap and the Challenging Behaviour Foundation (2021) ‘Tea, Smiles and Empty Promises: Winterbourne View, and a decade of failures - a collection of family stories’. Mencap and the Challenging Behaviour Foundation.

NHS England (2018) ‘Care and Treatment Reviews: Reporting in the Mental Health Services Data Set (MHSDS)’. NHS England. Available at: https://www.england.nhs.uk/wp-content/uploads/2018/09/mhsds-ctr-guidance-v1.pdf (Accessed: 7 October 2023).

healthwatch
Norfolk

Healthwatch Norfolk
Suite 6 The Old Dairy Elm Farm
Norwich Common
Wymondham
Norfolk
NR18 0SW

www.healthwatchnorfolk.co.uk
t: 0808 168 9669
e: enquiries@healthwatchnorfolk.co.uk
@HWNorfolk
Facebook.com/Healthwatch.norfolk